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van Delft-Schreurs, C.C.H.M.

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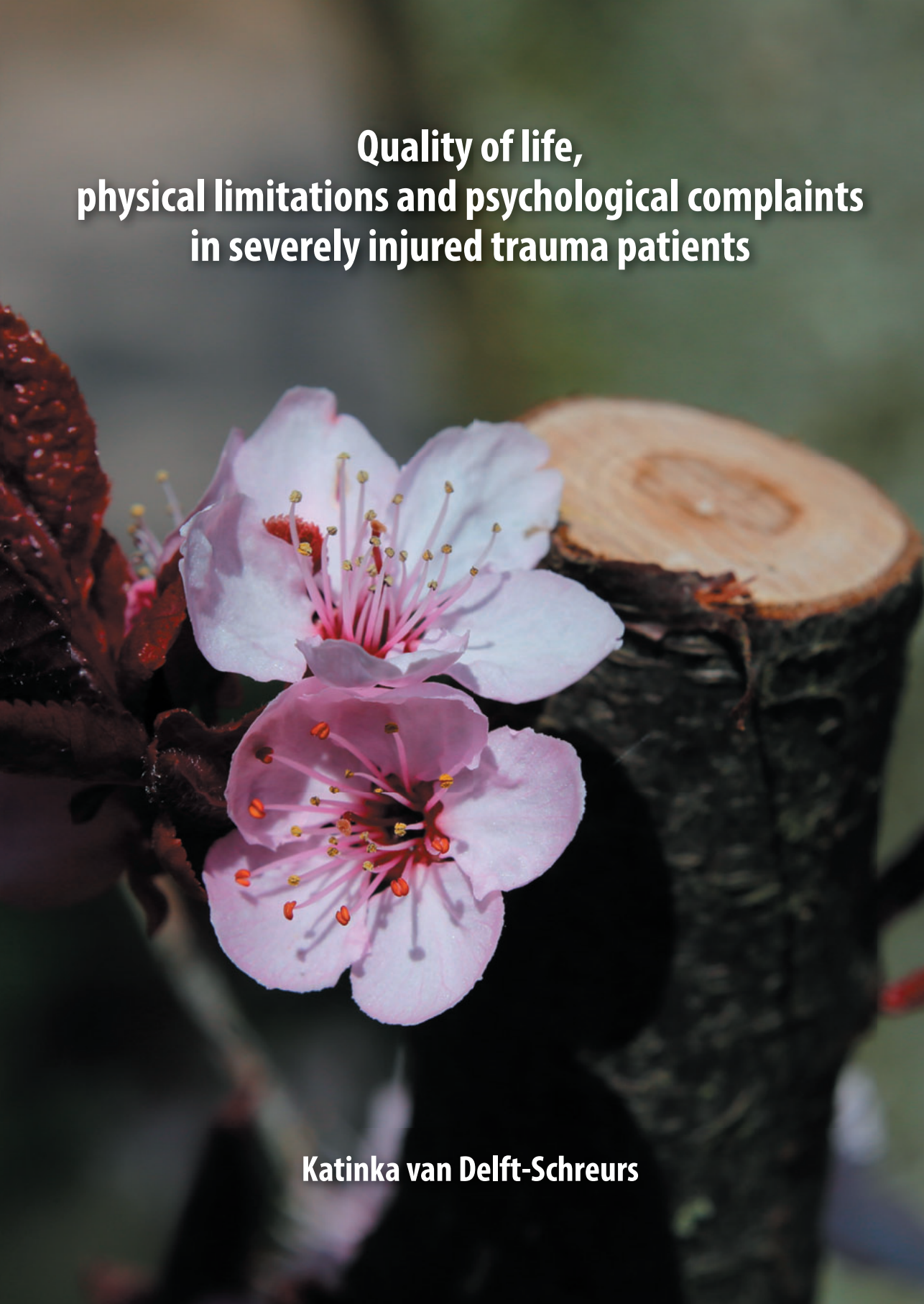

Katinka van Delft-Schreurs

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Catharina Christina Hermanna Maria van Delft-Schreurs
geboren op 24 september 1974 te Valkenswaard.

Promotores:

Prof. dr. J. de Vries
Prof. dr. M.H.J. Verhofstad

Copromotor:

Dr. M.A.C. de Jongh

Overige leden promotiecommissie:

Prof. dr. H.J.J.M. Berden
Prof. dr. L.P.H. Leenen
Prof. dr. J.A. Roukema
Dr. J.A. Haagsma
Dr. M. El Moumni

TABLE OF CONTENTS

CHAPTER 1

General introduction, aim and outline of this thesis

TRAUMA PATIENTS

Trauma, defined as getting physically injured in an accident, by violence or self-harm, is a health problem that is also a major cause of death. Annually almost 82,000 patients are admitted to a Dutch hospital because of their injury.[1] Almost half of these patients is younger than 60 years old. Most patients got injured by an accident at or around home (59%). About 20% was involved in a traffic accident.[1] The Dutch Trauma Registry (DTR) was introduced to gain more insight in the scale of this health problem in the Netherlands. All patients who are admitted in hospital in the Netherlands within 48 hours after their accident, are recorded in this DTR.

All separate injuries of the patients in the DTR are classified using the Abbreviated Injury Scale (AIS) coding system. This system is based on an anatomical classification, structured by body region and –structure. The severity of each injury is incorporated in each individual AIS code that provides information about the type of injury, the injured anatomical structure and its severity. However, patients often have multiple injuries. From all AIS codes, an overall injury severity score of the patient is calculated, the Injury Severity Score (ISS). This ISS correlates with survival chances. Different studies have confirmed the validity of the ISS as a predictor of death.[2] An ISS of 16 is predictive of 10% mortality and defines major trauma based on anatomic injury.[3] Therefore, patients with an ISS > 15 are called severely injured patients or polytrauma patients. Thus, a polytrauma patient is defined as a patient with an ISS score of 16 or higher, independent of the number of injuries. In recent years, 5 to 6 percent of the more than 80,000 patients who are annually registered in the DTR were severely injured. Most severely injured patients are males between 20 and 30 years old or more than 50 years old. Most patients have at least a serious head (55%) or thorax (39%) injury. More than half of the severely injured patients (57%) were admitted at a medium or intensive care department of a hospital.[1]

OUTCOME PARAMETERS

Mortality

Survival rates are the most common, obvious and objective outcome parameter used in trauma studies. In the Netherlands, 2% of all admitted patients don't survive their injury and 82% of these patients is 65 years or older. The mortality rate of severely injured patients (ISS > 15) is 16%.[1] By far most of the Dutch severely injured patients who survive are relatively young persons, as 66% of them are younger than 65 years

old.[1] Especially in countries with advanced health care systems, survival from trauma has increased in recent decades.[4] So, a lot of relatively young trauma survivors may have to live with long-lasting or permanent disabilities, which goes hand in hand with high costs for society, like medical expenses, rehabilitation programs, and loss of working years. This, in addition to a growing interest in appropriate care such as Value Based Health Care (VBHC), causes an increasing demand for outcome parameters assessing the burden after an injury, such as Health Status (HS) and Quality Of Life (QOL). VBHC incorporates patient relevant medical outcome parameters prominently.

Quality of Life

QOL is used as an overarching term. There are studies examining patients' functional status, i.e. focusing only on physical functioning, mostly from health care professionals' point of view. Most studies examine HS, which focus on patients' functioning in a physical, psychological and social domain.[5-7] In such studies, patients are asked to which extent their physical, psychological, and social functioning are limited, but they are not asked about their satisfaction with their functioning. According to the definition of the World Health Organization, patients' satisfaction is the core of the definition of QOL.[8;9] Thus, in Health Related Quality Of Life (HRQOL) studies, this satisfaction with functioning is incorporated in the same domains as in HS studies. So, patients are not only asked about their limitations or HS (e.g. Do you have problems with walking?), but are also asked how much they are bothered by this limitation (e.g. How much are you bothered by your difficulties with walking?). Those questions may be answered differently; a wheelchair patients for example have a lot of physical limitations. One patient may feel bothered by these limitations. Another patient does not feel bothered, because of the existing possibilities and can even take part in the Olympics. This may result in two patients with a comparable low physical HS, but a different HRQOL.

There also exist studies in which more QOL domains are examined, like the environment domain. These domains are added to the physical, psychological and social domain of the HRQOL questionnaires. Previous studies reported a decreased QOL for severely injured patients.[10-16] This conclusion was mainly based on HS and HRQOL assessment. Many factors are associated with HRQOL after an injury. Previous studies showed that age, gender, ICU days, comorbidity, posttraumatic stress symptoms, serious injury of the extremities, a low socio- economic or a low education level[17-22] were associated with non-fatal outcome after an injury.

Although consequences of an injury are often long lasting or even permanent, most previous studies measured outcome until two years after the injury. Mid-term outcome,

at the end of the patients' rehabilitation phase (15-53 months post-injury) is addressed in **chapters 2 to 6** of this thesis. Long-term outcome (approximately 10 years post-injury) is discussed in **chapter 6**. **Chapter 2** describes the mid-term QOL of the patients. Besides, it describes which investigated accident- and patient-related factors affected this QOL of severely injured patients. In **chapter 6** this is repeated for long-term QOL in the same group of patients.

Physical outcome

A severe injury may result in long-lasting physical disabilities or limitations.[23] These limitations of a person's physical functioning may be visible impairments, like an incapability to bend a leg or a lost limb, but it can also concern invisible impairments, like loss of muscle strength. Furthermore, brain injury can cause limitations of physical functioning. A patient may become less mobile or may be limited in some aspects of daily living because of the physical disabilities.

Physical disability is most commonly used to measure the burden of an injury. It was shown to be important for the decreased QOL of trauma patients.[24-26] Physical limitations are often determined by body region specific questionnaires. They were designed to measure physical limitations of a specific body region or of a specific injury or disease. Body region specific questionnaires are less useful in examining physical limitations in severely injured patients, because often multiple body regions are affected. As a consequence patients should have to complete several body specific questionnaires to gain the requested information, which would be time consuming and difficult concerning comparability. Therefore, for severely injured patients, it is desirable to use a more generic questionnaire. In this study the Short Musculoskeletal Function Assessment (SMFA), an internationally used generic questionnaire that is frequently used to determine HS and functional limitations, was used to determine physical limitations. Moreover, the SMFA was designed to measure HS and HRQOL of patients with a broad range of musculoskeletal injuries and disorders. Therefore, it seemed a promising questionnaire to provide information about both physical limitations and patients' satisfaction with functioning. However, validation of the Dutch version of this questionnaire was lacking. The psychometric properties of the adapted Dutch translation of the SMFA were examined in severely injured patients in **chapter 4** of this thesis. **Chapter 5** describes which factors were associated with mid-term physical residual symptoms. Residual functional disability at one year after an injury is often assumed to be everlasting. **Chapter 6** provides information about the physical limitations, about 10 years after the injury.

Psychological complaints

Psychological complaints cover a wide range of problems concerning abnormal or extreme thoughts and feelings, which are so distressing, unpleasant and upsetting to a person, that it interferes with his or her ability to conduct daily activities in a constructive way.[27] People with psychological complaints often feel gloomy, stressed, lonely, tired, worried, anxious, or irritated and often find it hard to concentrate. Psychological complaints are often examined with questionnaires because (semi-)structured interviews take a lot of time of patients and researchers. The Hospital Anxiety and Depression Scale (HADS)[28;29] and the Impact of Events Scale (IES)[30;31] are often used to examine symptoms of anxiety and depression disorders or a posttraumatic stress syndrome (PTSS), respectively. Such disorders contain a certain well defined combination of symptoms of which the extend of which they are experienced determines the diagnosis. Questionnaires can indicate the extend of symptoms and are, therefore, good screening tools for the disorders.

Shocking experiences like an accident are known to cause psychopathology like a PTSS, but also anxiety, depressions, and subjective cognitive complaints may occur. A relationship is found between posttraumatic psychological problems and impaired QOL.[20;32-35] So, besides physical aspects, psychological complaints also seem to play an important role in the decreased QOL of trauma survivors.[17;20;24;36] A strong correlation was found between increased physical limitations and posttraumatic psychopathology.[32] However, the causality in this interaction is unclear. Psychological complaints may worsen somatic complaints and vice versa. A psychological reaction may possibly have an underestimated effect on QOL, as psychological complaints often are less visible and get less attention than physical limitations. In **chapter 3**, the mid-term psychological complaints of the study population are described. Besides, QOL scores of a reference group of the general Dutch population are compared with QOL scores of subgroups of patients with and without psychological complaints. The relationship between mid-term psychological and physical complaints and QOL are described in **chapter 5**. **Chapter 6** provides information about the changes in the psychological situation 10 years after the injury in comparison with the situation 7 years earlier.

Personality

It is known that experienced QOL also depends on a person's personality.[37] A person's personality is a rather stable set of psychological features and mechanisms within the individual that causes his or her habitual behaviors, cognitions and emotional patterns in different situations.[38] This regulates how a person habitually reacts in different situations and how he or she naturally tries to 'survive' difficult experiences. Personality is often determined according to the five personality traits of the Five Factor

Model with the NEO-Five Factor Inventory (NEO-FFI).[39] This questionnaire measures the traits: Neuroticism, Extraversion, Openness to new experiences, Agreeableness, and Conscientiousness. The experienced QOL mainly seems to be influenced by the features Neuroticism and Extraversion.[40]

Neuroticism is the tendency to experience frequent and intense negative affective states (like anxiety or irritability) as stress response. Extraversion is a tendency towards sociability, assertiveness, and positive affection. A personality trait that is closely related to Neuroticism and has shown to play an important role in the QOL of, for instance, women with breast cancer or a benign breast problem, is Trait anxiety.[41;42] Trait anxiety refers to the tendency to experience anxiety across situations and may be relevant in severely injured patients as well.[43]

Associations between personality characteristics and QOL were described in orthopedic[44;45] and oncological studies.[46;47] So, the patients' personality may also be important for the extent to which a person feels bothered by existing physical limitations and the level of experienced satisfaction with his or her situation. The association between the patients' personality and their long-term QOL, psychological complaints and physical limitations is described in **chapter 6**.

AIM OF THIS THESIS

Most severely injured patients survive. They often have to live with long-lasting or permanent residual symptoms. Little is known about the mid-term and long-term QOL of these survivors and about factors that may influence their long-term QOL. Therefore, this dissertation aimed to get more insight into mid-term and long-term physical limitations, psychological complaints and QOL of severely injured patients (ISS> 15) more than one and more than 10 years after their injury. This resulted in the following research questions that are examined in this thesis:

1. Are the mid- and long-term QOL, physical and psychological conditions of severely injured patients comparable with the scores of the Dutch population?
2. Are mid- and long-term QOL associated with the patients' demographic- or medical characteristics?
3. What is the incidence of psychological complaints within this group of patients?
4. How many patients received psychological or psychiatric help?
5. Is there an association between psychological complaints and QOL?
6. Is the Dutch translation of the SMFA suitable for measuring physical limitations and HRQOL for severely injured patients?
7. Do physical complaints contribute to a reduced QOL?
8. Is there a relationship between the mid- and long-term QOL, physical limitations and psychological complaints?
9. Did the long-term outcome, approximately ten years after a severe injury, change compared to 7 years earlier?
10. Is there an association between the patients' personality and long-term outcome?

More knowledge concerning these issues may be useful to provide severely injured patients with appropriate care and provide insight into which patients are at risk for a lower QOL at an early stage. It can be part of a specific form of 'Value based healthcare'.

OUTLINE OF THIS THESIS

QOL, psychological complaints and physical limitations of severely injured patients were investigated 15-53 months after their accident (Time 1) and 7 years later (Time 2). In **chapter 2** the QOL of the study population at Time 1 is compared with QOL scores of a reference group of the general Dutch population. In addition, the results of subgroup analyses are presented and relationships between characteristics of the patients, the accident or injuries and mid-term QOL are discussed.

Chapter 3 describes the incidence of psychological complaints and the relationship between psychological complaints, QOL and patient- or accident-related factors.

The Dutch adapted version of the SMFA and the psychometric properties of this questionnaire in severely injured patients are examined in **chapter 4**.

In **chapter 5** the relationship between the physical functioning and injury- or patient-related factors is examined. Furthermore, the association between QOL, psychological complaints and physical limitations is addressed.

The patients of our study population who were still alive 10 years after their injury were reassessed and asked to provided information about their outcome in a similar way as 7 years before (Time 2). The outcome was compared with their outcome 7 years earlier. In addition, the association between this long-term outcome and the personality of the patients is presented in **chapter 6.** Finally, **chapter 7** contains the general discussion, in which the main findings of chapter 2 through 6 are summarized and discussed.

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CHAPTER 2

Quality of life in severely injured patients depends on psychosocial factors rather than on severity or type of injury

C.C.H.M. van Delft-Schreurs
J.J.M. van Bergen
M.A.C. de Jongh
P. van de Sande
M.H.J. Verhofstad
J. de Vries

Injury 2014; 45(1): 320-326.

ABSTRACT

Background

Former studies have demonstrated that health-related quality of life is decreased in severely injured patients. However, in those studies patients were asked about their functioning and not about their (dis)contentment concerning their functioning. Little is known about how severely injured patients experience their quality of life (QOL). The objective of this cross-sectional study was to measure this subjective QOL of severely injured patients after their rehabilitation phase and to examine which accident- and patient-related factors affect the QOL of these patients.

Methods

Patients of 18 years or older with an injury severity score (ISS) above 15 were included 15-53 months after their accident. Comorbidity before the accident, accident and sociodemographic characteristics, and QOL were obtained from the trauma registry and questionnaires. The WHOQOL-BREF was used to measure QOL. A reference group of the Dutch general population was used for comparison.

Results

The participation rate was 61% (*n*=173). Compared with the reference data, severely injured patients experienced a significantly worse QOL in all domains except social relations. The QOL scores were significantly decreased in all domains for patients with neurological injury in combination with other injuries. Patients with a severe intracranial injury (AIS>3) only reported significantly impaired QOL in the general and physical domains. Patients who resumed working or lived with others had significantly higher scores in all domains of QOL than patients who did not work anymore or were living alone. Significantly lower QOL scores were obtained from patients with comorbidity before the accident and from patients with longer durations of intensive care unit (ICU) treatment or hospitalization. Gender, accident characteristics and time since the accident did not appear to be important for experienced QOL.

Conclusions

The experience of impaired QOL appears to depend on living alone, inability to return to work and pre-accidental comorbidity rather than on the injured body area or the severity of the injury. Duration of hospital or ICU stay is important to subsequent QOL, even if ISS or body region is not.

INTRODUCTION

The outcome parameter most commonly used in trauma care studies is mortality. However, the majority of trauma patients survive their injury. Serious injuries often result in varying types of disability. This disability has numerous social and economic consequences because it frequently concerns young patients, who often become unfit to return to work, to regain their previous levels of activity or to reintegrate back into society.[1] Therefore, interest in trauma care studies has begun to focus more and more on the quality of life (QOL) of trauma survivors. The few existing studies reported that the QOL in severely injured patients is decreased.[2-8] However, this observation is based on health related quality of life (HRQOL) or health status studies. Health status has been defined as the impact of disease on a patient's physical, psychological and social functioning.[9-11] In health status studies, patients are asked about their functioning, thereby focusing on disabilities, and not about their (dis)contentment concerning their functioning.[12] In contrast, QOL as defined by The World Health Organization Quality of Life Group (WHOQOL group) is: "the individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards and concerns".[13] Therefore, it also asks patients about their satisfaction with their functioning. The core of this definition is that QOL refers to patients' evaluation of functioning in line with their expectations.[14] Thus, where health status only concerns patients functioning, QOL also includes patients' satisfaction with functioning. Little is known about this QOL in severely injured patients.

The first objective of our study was to measure the experience of QOL among severely injured patients after their rehabilitation phase. The second objective was to examine which accident-related factors and patient-related factors affect the experience of QOL of these patients.

PATIENTS AND METHODS

Patients

Trauma patients who were hospitalized in the St. Elisabeth Hospital between 1-1-2006 and 12-31-2008, were asked to participate if they had been severely injured (Injury Severity Score (ISS) >15) and were 18 years or older at the start of the study, still alive and had a traceable postal address. The patients or their caregivers decided whether or not they were able to answer a questionnaire that was sent by postal mail. The patients were included after written informed consent was obtained and if the questionnaires

(described below) were completed and returned. When patients did not participate, they were called and asked for the reason and for some basic information on their health status using a 3 point likert scale from 'good' to 'not good at all'.

Patient characteristics

Demographic data (age, gender, household composition, education, being at work), characteristics of the accident (traffic, at work, at home, sports, attempted suicide), and medical data (injury, duration of hospitalization and Intensive Care Unit (ICU) treatment) were extracted from the trauma registry and a general questionnaire consisting of questions on socio-demographics, the accident, and their health situation before the accident.

Type of injury and injured body area

The Abbreviated Injury Scale (AIS) and ISS were used to determine the injured body area and severity of the injuries. The AIS is anatomically based and classifies each injury by body region on a scale from 1 (minor) to 6 (non-survivable).[15] The ISS is the sum of the square of the AIS for the three most serious injuries in different ISS body regions and yields scores for the overall severity of the injury from 1 to 75.[16;17]

Quality of life

The Dutch version of the World Health Organization Quality of Life assessment instrument-BREF (WHOQOL-BREF) was used to measure QOL.[18;19] This instrument was used because it is a generic, cross-culturally developed comprehensive questionnaire measuring QOL, which measures a person's subjective perceptions about their life with respect to their goals, concerns, and satisfaction. It consists of questions within the domains of physical health (7), psychological health (6), social relationships (3), and the environment (8), as well as general (2) questions on QOL and general health. Each question has a five-point response scale. The domain scores denote an individual's perception of their QOL in each particular domain and are scaled in a positive direction (i.e., higher scores denote higher QOL). The reliability and validity of the WHOQOL-BREF are good.[20;21] The domain values were calculated for each patient in our study and compared with the scores from a reference group of the Dutch general population with a mean age of 54 (SD 16) years old. [22]

Statistical analysis

Independent sample t-tests were used for continuous variables and Chi-square tests for categorical variables to compare the group of non-respondents with the respondents. One-sample t-tests were employed to compare the QOL of the traumatized patients and

subgroups of patients with and without intracranial injury with data from a reference group of the WHOQOL-BREF.[22] To investigate accident- and patient-related predictors of QOL, univariate linear regression analyses were performed. Multivariable linear regression analyses were performed to investigate whether the injured body area affected QOL. For a comparison of QOL among patients groups with different types of injuries, the data were analyzed with an ANOVA and, if a main effect was found, also a post hoc Tukey test was performed. The data were analyzed using IBM SPSS statistics 19 software (SPSS Chicago, IL, USA; version 19.0). The significance level was $p<0.05$ for all of the tests used.

RESULTS

Patients

In the St. Elisabeth Hospital, 3195 trauma patients were hospitalized in the years 2006, 2007 and 2008, including 470 severely injured patients (ISS>15). Before the study started, 144 of these patients had already died (31%), 24 patients were younger than 18 years old (5%) and 21 patients were untraceable (4%). The remaining 281 patients were eligible to participate, and 173 of them returned the questionnaires (a response rate of 62%) 15-53 months after their accident. The selection procedure is shown in figure 1.

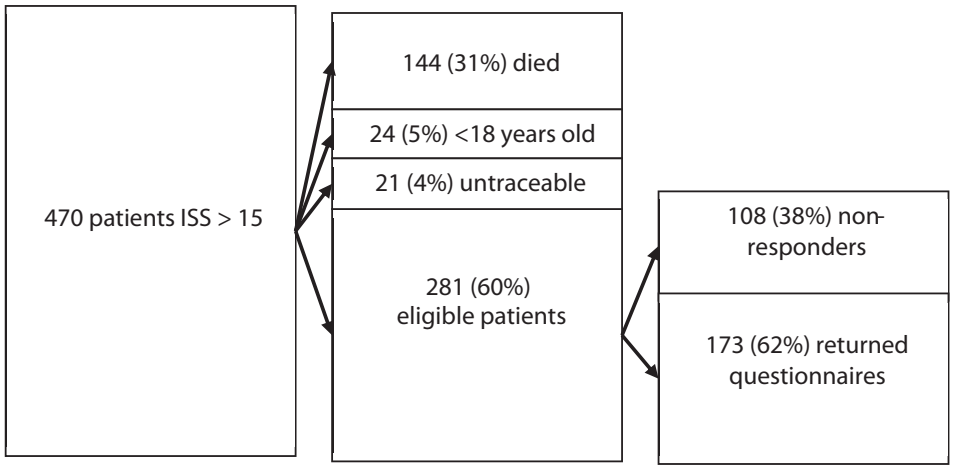

Figure 1. Flow chart of selection of eligible patients

Slightly more than half of the non-respondents *(n*=108) could be contacted by phone (*n*=56) to ask them for their actual health status and reason for not participating (the results are represented in table 1). Most of them were not interested (62%), and 14% did not want to be contacted any more. For 16% of the patients, their health status was too poor to participate. One third of the contacted non-respondents declared that they did not feel well at all.

Table 1. Reasons for refusal to participate and the health status of the non-respondents. Severely injured patients, St Elisabeth Hospital 2006-2008.

Reason	Health status				Total
	Good	Some disabilities	Not good at all	Unknown	
Not interested	9	8	6	12	35
Does not want to be contacted	2	3	3		8
Unable to participate		1	9	3*	13
Untraceable by phone				52	52
Total	11	12	18	67	108 non-respondents

* because of language problems

The respondents and non-respondents did not differ significantly with respect to age, injured body area, severity of the injury, duration of hospitalization, or ICU care (see table 2). Although both groups mainly consisted of males, the females responded significantly more often than the males, based on a comparison of the respondent with the non-respondent group (31% vs. 15%; *p*=0.003).

Table 2. Comparison between respondents and non-respondents.
Severely injured patients, St Elisabeth Hospital 2006-2008.

n=281		Respondent		
		Yes	No	p-value
Age		47 (SD 19)	44 (SD 20)	0.237
Gender	Male	*n*=120	*n*=92	0.003*
	Female	*n*=53	*n*=16	
ISS		23 (SD 8)	23 (SD 8)	0.446
Duration of hospitalization		25 (SD 24)	24 (SD 29)	0.809
Duration of ICU stay		15 (SD 20)	15 (SD 18)	1.000
Head	Yes	*n*=131	*n*=79	0.629
	No	*n*=42	*n*=29	
Face	Yes	*n*=131	*n*=79	0.638
	No	*n*=42	*n*=29	
Thorax	Yes	*n*=71	*n*=35	0.146
	No	*n*=102	*n*=73	
Abdomen	Yes	*n*=30	*n*=20	0.802
	No	*n*=143	*n*=88	
Spine	Yes	*n*=38	*n*=18	0.297
	No	*n*=135	*n*=90	
Upper extremities	Yes	*n*=53	*n*=34	0.881
	No	*n*=120	*n*=74	
Lower extremities	Yes	*n*=53	*n*=80	0.396
	No	*n*=120	*n*=28	

p-values, means and SD are shown for continuous variables and p-values and the numbers of patients per variable for categorical variables.
* $p<0.05$

Patient characteristics

Patient characteristics are presented in table 3. Most patients were male and did not live alone. The mean age was 47 (SD 19) years, and most injuries were caused by traffic accidents. The most common injury was intracranial injury (61%). Serious intracranial injury (AIS>3) was present in 52% of the cases. The median ISS was 21 (range between first quartile (17) and third quartile (27)), and 86% of the patients had received ICU treatment. The questionnaires were completed between 1.3 and 4.4 years after the injury, and the mean time since the injury was 2.8 (SD 0.9) years.

Table 3. Patient characteristics. Severely injured patients, St Elisabeth Hospital 2006 - 2008.

Social-demographic characteristics (n=173)	**category**	**n**	**%**
Age at start of the study	< 55	111	64
	>=55	62	36
Gender	Male	120	69
	Female	53	31
Education level*	Basic	33	19
	Middle	86	50
	High	44	25
Household*	Alone	40	23
	Together	131	76
Living together with*	Partner	55	32
	Children	9	5
	Partner and children	36	21
	Parents	23	13
	Students	3	2
Had work at time of injury		113	65
Returned to work after injury*		54	31
Accident-related characteristics (n=173)		**n**	**%**
ISS	16 - 25	97	56
	>=25	76	44
Mechanism of accident	Blunt	166	96
	Penetrating	7	4
Type of accident*	Traffic	93	54
	At home	33	19
	At work	10	6
	Sports	8	5
	Raid	2	1
	Attempted suicide	3	2
	Other type of accident	23	13
At least one injury in this AIS region	Head	131	76
	Intracranial	105	61
	Face	46	27
	Thorax	71	41
	Abdomen	30	17
	Spine	38	22
	Transverse myelitis	12	7
	Upper extremity	53	31
	Lower extremity	53	31

Table 3. Continued

Comorbidity before trauma (n=173)	n	%
Physical comorbidity*	43	25
Medication use*	67	39
Mental treatment*	16	10
Medication for psychological disorders	13	8

*Category unknown: Education level: 10, Household: 2, Living together with: 5,. Returned to work after injury: 4, Physical comorbidity: 1, Medication use: 4, Mental treatment: 1.

Quality of life

Compared with a reference group of the general Dutch population (mean age 54 (SD 16) years), the severely injured patients had a worse QOL in all domains except social relations (see table 4).

The QOL scores of the subgroup of patients with intracranial injury combined with other injuries were significantly decreased in all domains compared with the scores of the reference group. The subgroup of patients with severe intracranial injury (AIS>3) only scored significantly lower QOL for the domain physical health. The general QOL, psychological health and environment domains did not differ significantly from controls, nor did they differ significantly from the other injury groups. Only on the social domain a main difference was found between the three subgroups (p=0.039), i.e., the group with no intracranial injury scored significantly better than the group with combined injury (p=0.029).

The subgroup of patients without intracranial injury reported a significantly decreased QOL in the domains general, physical health and environment compared to the reference group (see table 4).

The time from the accident to questionnaire completion was not significantly related to the QOL. The QOL was not found to be affected by sex or age, except for age in the environmental domain, in which older patients report better QOL than younger patients.

Patients who had resumed working or who lived with others reported significantly higher scores in all QOL domains. Patients with a longer duration of hospitalization (p=0.007), a longer duration of ICU treatment (p=0.016) or comorbidity before the accident (physical comorbidity: p=0.006, mental treatment: p=0.036) had significantly lower QOL scores in the physical domain. Patients with mental treatment before the injury had significant lower QOL scores in the psychological domain. The betas of the linear regression analysis are fairly consistent for duration of hospitalisation, duration of ICU treatment, physical comorbidity and mental treatment. When comparing patients with injuries in different

body areas, significant effects were only found for environmental QOL. Patients with spinal injury reported a significantly impaired environmental QOL, and patients with thoracic injury reported a significantly better environmental QOL than patients with other injuries. No association was found between QOL and accident characteristics, the severity of the injury, or whether or not a patient received ICU treatment. Comparisons of the QOL scores using linear regression are shown in table 5.

Table 4. Comparison of QOL between severely injured patients of St Elisabeth Hospital, 2006-2008 and the general Dutch population.

Domain	General Dutch population	Multi-trauma Patients *n*=167	No intracranial injury *n*=66	Isolated serious intracranial injury (AIS>3)** *n*=38	Intracranial injury combined with other injury *n*=63	One-way between-groups ANOVA*** p-value
General						
Mean (SD)	7.8 (1.6)	7.1 (1.8)*	7.3 (1.7)*	7.2 (1.8)	6.9 (1.8)*	
p-value		<0.001	0.027	0.063	< 0.001	0.439
Physical health						
Mean (SD)	15.5 (2.7)	14.2 (3.5)*	14.2 (3.7)*	14.3 (3.4)*	14.1 (3.5)*	
p-value		<0.001	0.006	0.034	0.002	0.984
Psychological health						
Mean (SD)	14.7 (2.2)	14.1 (3.0)*	14.6 (2.9)	13.9 (3.1)	13.6 (3.1)*	
p-value		0.010	0.753	0.126	0.011	0.234
Social relationships						
Mean (SD)	15.2 (2.9)	14.8 (3.2)	15.5 (2.6)†	14.9 (3.3)	14.1 (3.5)*†	
p-value		0.149	0.293	0.568	0.015	0.039*
Environment						
Mean (SD)	15.9 (2.2)	15.1 (2.8)*	15.1 (2.6)*	15.2 (3.1)	15.1 (2.9)*	
p-value		<0.001	0.020	0.141	0.030	0.954

One sample t-tests were employed to compare the QOL of traumatized patients with data from a reference group of the Dutch general population, and to compare several subgroups with this reference group. The mean WHOQOL-BREF scores and SD are shown. QOL scores could not be determined for one patient without intracranial injury and one patient with intracranial injury in the general domain and for two patients with intracranial injury for the domain physical health.

* $p<0.05$

** There are no patients with isolated intracranial injury with an AIS≤3.

*** The p-value concerns the main effect of the comparison between the three subgroups. Individual p-values need to be interpreted cautiously when this ANOVA is non-significant.

† Post hoc Tukey test: p=0.029.

Table 5. Results from linear regression analysis for patient characteristics, injury characteristics and treatment on quality of life. Severely injured patients, St Elisabeth Hospital 2006-2008.

WHOQOL-BREF	General		Physical		Psychological		Social		Environment	
	Beta	95% CI	Beta	95% CI	Beta	95% CI	Beta	95% CI	Beta	95% CI
Age	0.110	(-0.004 - 0.025)	0.032	(-0.023 - 0.035)	0.061	(-0.015 - 0.034)	0.032	(-0.020 - 0.031)	0.174	(0.003 - 0.048)*
Gender male	-0.051	(-0.787 - 0.397)	-0.085	(-1.844 - 0.528)	-0.099	(-1.641- 0.354)	0.049	(-0.709 - 1.379)	0.045	(-0.655 - 1.202)
Living together	0.243	(0.384 - 1.634)*	0.203	(0.422 - 2.954)*	0.175	(0.163 - 2.316)*	0.237	(0.641 - 2.841)*	0.200	(0.326 - 2.320)*
Returned to work after injury	0.410	(0.814 - 2.054)**	0.539	(2.572 - 4.817)**	0.393	(1.291 - 3.406)**	0.212	(0.148 - 2.519)*	0.413	(1.368 - 3.388)**
Physical comorbidity before injury	-0.125	(-1.134 - 0.118)	-0.213	(-2.960 - -0.495)*	-0.099	(-1.757- 0.378)	-0.115	(-1.949 - 0.276)	-0.150	(-1.953 - 0.016)
Mental treatment before injury	-0.195	(-2.073 - -0.258)*	-0.164	(-3.781 - -0.133)*	-0.280	(-4.389 - -1.361)**	-0.122	(-2.937 - 0.327)	-0.150	(-2.874 - 0.017)
ISS	-0.009	(-0.038 - 0.034)	-0.016	(-0.080 - 0.065)	-0.050	(-0.080 - 0.041)	-0.043	(-0.081 - 0.046)	0.020	(-0.049 - 0.064)
Body region***										
Head	-0.133	(-1.279 - 0.202)	-0.055	(-1.920 - 1.027)	-0.112	(-2.094 - 0.397)	-0.168	(-2.520 - 0.088)	-0.090	(-1.703 - 0.537)
Face	-0.022	(-0.772 - 0.593)	-0.078	(-1.972 - 0.719)	-0.082	(-1.694 - 0.580)	-0.056	(-1.584 - 0.796)	-0.081	(-1.536 - 0.509)
Thorax	0.063	(-0.404 - 0.854)	0.088	(-0.622 - 1.888)	0.065	(-0.667 - 1.457)	0.064	(-0.703 - 1.521)	0.213	(0.252 - 2.163)*
Abdomen	-0.003	(-0.808 - 0.782)	0.035	(-1.251 - 1.885)	0.022	(-1.157 - 1.510)	-0.035	(-1.687 - 1.105)	-0.039	(-1.481- 0.918)
Spine	-0.102	(-1.133 - 0.276)	-0.158	(-2.756 - 0.81)	-0.110	(-1.988 - 0.397)	-0.057	(-1.677 - 0.820)	-0.233	(-2.632 - -0.486)*
Upper extremities	-0.043	(-0.777 - 0.443)	-0.024	(-1.758 - 0.688)	-0.101	(-1.695 - 0.368)	0.019	(-0.948 - 1.212)	-0.142	(-1.797 - 0.058)
Lower extremities	-0.084	(-0.989 - 0.337)	-0.069	(-1.507 - 1.126)	-0.033	(-1.326 - 0.896)	0.007	(-1.114 - 1.213)	-0.011	(-1.069 - 0.929)
Duration of hospitalization	-0.124	(-1.020 - 0.002)	-0.210	(-0.053 - -0.009)*	-0.147	(-0.037 - 0.001)	-0.145	(-0.038 - 0.001)	-0.158	(-0.036 - -0.001)*
ICU treatment y/n	-0.055	(-.091 - 0.517)	-0.006	(-1.668 - 1.550)	-0.024	(-1.584 - 1.160)	0.022	(-1.224 - 1.638)	-0.041	(-1.608 - 0.935)
Duration of ICU treatment	-0.114	(-0.024 - 0.004)	-0.201	(-0.065 - -0.007)*	-0.100	(-0.040 - 0.010)	-0.177	-0.052 - -0.002*	-0.082	(-0.035 - 0.012)

In the upper and lower parts of the table univariate regressions were used. Multiple regression was only used for the body areas. Beta and the 95% confidence intervals for the unstandardized regression coefficients from a clarifying linear regression model are shown.
* $p<0.05$
** $p<0.001$
***Injury in this AIS body region, regardless of the severity, adjusted for the other body regions.

DISCUSSION

The first objective of our study was to measure the experienced QOL of severely injured patients after their rehabilitation phase. This was accomplished by comparing the QOL of a sample of severely injured trauma patients with a sample from the general Dutch population. The patients experienced an impaired QOL in all domains except the social domain. This finding suggests that patients are satisfied with the social support they receive. The largest impairment in QOL was in the physical domain. Alves *et al.* also found that the social WHOQOL-BREF scores were affected less and the physical WHOQOL-BREF scores were affected most six months after discharge in a less severely injured population, compared with samples of the general population.[23]

The second objective was to examine which accident-related factors and patient-related factors affect the QOL of severely injured patients after their rehabilitation phase. In contrast with HRQOL studies that found that poor HRQOL outcome was associated with higher age,[8;24-26] we observed that older patients (≥ 55 years) reported a better physical QOL than younger ones. In the general Dutch population, older people report a decrease in physical QOL but not in psychological QOL.[27] We suggest that older trauma patients had other or fewer expectations about their (physical) QOL compared with younger patients. These latter patients likely wanted their lives to return to normal so they could fulfill their roles in life again and were disappointed.

The relationship between gender and HRQOL outcomes appears inconsistent. We found no relationship, in accordance with a number of studies,[2;25;28] whereas women were found to be at risk of worse HRQOL outcomes in several other studies.[6;8;26;29] As women reported lower QOL scores in the general Dutch population,[27] it is possible that female patients find it less difficult to accept that they must live with the sequelae of the accident than males. Other sociodemographic aspects (living alone and being unable to return to work) and pre-traumatic comorbidity, psychological as well as physical, are related to impaired QOL. This result is consistent with previous HRQOL studies.[6;8;30;31]
In agreement with most HRQOL studies, [7;24;32-34] we found no relationship between ISS and QOL. This independence is likely due to the fact that the ISS is defined to calculate the mortality risk.[16] Once a patient has survived, this value may well differ from the severity in terms of the remaining sequelae. Therefore, the ISS does not appear to be suitable for measuring the severity in terms of QOL.

Concerning the injured body areas, an impaired QOL was only found for patients with vertebral injury, and only in the environmental domain. A significantly better

environmental QOL was reported by patients with thoracic injury. The results with regard to environmental QOL have not been examined in other studies because the WHOQOL instruments are one of the few that assess this domain of QOL. Spinal cord injury, lower extremity injury and brain injury were mentioned as predictors of poor functioning in the long term, and patients without intracranial injury reported a better long-term outcome of QOL in former studies.[30;31;35] In other HRQOL studies, in which patients with traumatic brain injury were compared with a non-injured reference group, major problems were found in the social domain.[34;36] This observation is consistent with the results found in our study, in which the subgroup of patients with intracranial injury in combination with other injuries also reported an impaired QOL in the social domain, compared with the subgroup patients without intracranial injury. Furthermore, this was the only domain in which the total study population did not report an impaired QOL compared with the reference group. Patients with isolated severe intracranial injury (AIS>3) only reported an impaired QOL for the domains of general and physical health. In our study, this is most probably due to the lower sample size of this group, considering the fact that the mean scores for the three subgroups is approximately the same. However, in several other studies, patients with severe head injury appeared to be better off than patients without severe head injury[37] or patients with less severe traumatic brain injury.[38] The experience of QOL may be better than expected based on the severity of the head injury and the remaining limitations, due to cognitive changes causing reduced insight into their own limitations and the effects on daily life.

The duration of hospitalization and duration of ICU treatment were also found to be correlated with decreased physical QOL scores. This observation is in agreement with results found in an HRQOL study.[24] So duration of hospitalization and ICU treatment may be important to subsequent QOL, even if body region is not.

Using different types of measures may result in different results for HRQOL and QOL.[39] In patients with intermittent claudication, Breek *et al.* found that patients with excellent and very poor QOL scores were found in nearly all the quartiles of the corresponding HRQOL domains.[40] However, in severely injured patients, factors that seem to be important for being satisfied with functioning are mainly in agreement with factors found to be important for the functioning itself in HRQOL studies, except for age. In accordance with HRQOL studies, we found that longer duration of hospitalization or ICU treatment, living alone, being unable to return to work and pre-traumatic comorbidity, are related to impaired QOL and that a relationship between ISS and QOL is absent.

Although conflicting results are found in the literature about variation of QOL over time,[41,35,42] our results revealed that QOL is still decreased after the rehabilitation phase (1-5 years after the accident). This observation is in agreement with the results found at long periods after cerebral lesions by Teasdale and Engberg.[43]

Several limitations should be mentioned. The patients were asked retrospectively for their pre-accidental health status and mental treatment, as these data are always unknown in trauma care studies. Secondly, the response rate in this study was 61% of the eligible patients. However, the group of non-respondents was similar to the group of respondents, except for an overrepresentation of women. Because the QOL was not affected by gender in our study, this is not expected to bias the measured QOL. Furthermore, we compared our data with data from a reference group of the Dutch general population because no matched control group was available. The trauma patients were a slightly younger (7 years) than the reference group and contained mainly males, because severely injured patients are often younger males. We do not expect that this has affected the results, because we did not find significant relations between QOL and gender or age, except for age in the domain environment. The QOL of all patients may be overestimated in this study because 50 percent of the non-respondents, asked for a reason for not participating, indicated that they did not feel well at all or did not want to be remembered for the accident anymore. Moreover, half of the patients that did not feel well at all felt too unwell to participate. Therefore, the QOL may easily be even lower in the severely injured trauma population than was found in this study. Finally, except for the subgroup of patients with intracranial injury, the number of patients was too small to analyze subgroups.

CONCLUSION

Severely injured patients experience a lower QOL than the general Dutch population in all domains except social relations. The QOL was found to depend mainly on certain sociodemographic aspects (living alone and being unable to return to work) and pre-traumatic comorbidity, rather than the rehabilitation time after the accident, the severity of the injury or the injured body area. Duration of hospital or ICU stay is important to subsequent QOL, even if ISS or body region is not. This is in agreement with results found in HRQOL studies. The remaining physical limitations or psychological factors could, therefore, be more important for the experience of QOL than the severity of injury or the injured body area. Future studies should include prospective follow-up studies with larger subgroups in which the severity of the injury can be taken into account and analyses of patients with intracranial injury.

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CHAPTER 3

A cross-sectional study of psychological complaints and quality of life in severely injured patients

C.C.H.M. van Delft-Schreurs
J. J.M. van Bergen
P. van de Sande
M.H.J. Verhofstad
J. de Vries
M.A.C. de Jongh

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ABSTRACT

Purpose

The purpose of this study was to examine the incidence of psychological complaints and the relationship of these complaints with the quality of life (QOL) and accident- and patient-related factors among severely injured patients after the rehabilitation phase.

Methods

Patients of 18 years or older with an injury severity score (ISS) above 15 were included 15-53 months after their accident. Accident and patient characteristics were obtained from questionnaires and the trauma registry. Several questionnaires (Hospital Anxiety and Depression Scale, Impact of Events Scale and Cognitive Failure Questionnaire) were used to determine symptoms of psychological problems (respectively anxiety or depression, posttraumatic stress disorder or subjective cognitive complaints). The world health organization quality of life-BREF was used to determine QOL. A reference group of the Dutch general population was used for comparison of QOL scores.

Results

The participation rate was 62% (*n*=173). At the time of the study, 30.1% (*n*=52) of the investigated patients had psychological complaints. No relation between psychological complaints and somatic severity or type of injury was found. Patients who were employed before the accident or resumed working, reported less psychological complaints. Use of any medication before the accident and treatment for pre-accidental psychological problems were positively related to psychological complaints afterwards. QOL of severely injured patients was impaired in comparison with the general Dutch population, but only for those with psychological complaints.

Conclusions

Psychological complaints seem to be an important and underestimated factor for a decreased QOL among severely injured patients.

BACKGROUND

Severely injured patients experience decreased quality of life (QOL).[1-4] There are indications of a relationship between this impaired QOL and posttraumatic psychological problems or posttraumatic stress disorder (PTSD)[3;5-10] caused by shocking experiences, such as accidents. A psychological reaction may have an even greater effect on QOL than somatic disability. One study showed that patients reported considerable psychological problems five years after a major trauma.[1] However, most QOL observations are based on health-related quality of life (HRQOL) or health status studies. Health status has been defined as the impact of disease on a patient's physical, psychological, and social functioning.[11-13] In health status studies, patients are asked about their functioning, thereby focusing on disabilities, but not about their (dis)contentment concerning their functioning.[14] By contrast, the World Health Organization quality of life group (WHOQOL group) defines QOL as follows: "the individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards and concerns".[15] Therefore, it also asks patients about their satisfaction with their functioning. The core of this definition is that QOL refers to patients' evaluation of functioning in line with their expectations.[16] Thus, whereas health status only concerns patients' functioning, QOL includes patients' satisfaction with functioning. This QOL is decreased in severely injured patients.[17] However, the relation between QOL and psychological problems after an accident is not clear. Little is known about whether the type of accident, the seriousness of the injury or the injured body region affects the psychological problems of patients after the rehabilitation phase.

The main objective of the current study was to examine psychological complaints (anxiety, depression, PTSD or subjective cognitive complaints) in severely injured patients after the rehabilitation phase. The three specific objects were: (1) to determine the incidence of psychological complaints, (2) to investigate the relationship of psychological complaints with accident- and patient-related factors, and (3) to examine the relationship of the psychological complaints with QOL.
The study was approved by the Medical Ethical Review Board of the St. Elisabeth Hospital.

PARTICIPANTS AND METHODS

Participants

In the St. Elisabeth Hospital, 3195 trauma patients were hospitalised in the years 2006, 2007 and 2008, including 470 severely injured patients (injury severity score (ISS) > 15). Those severely injured patients were asked to participate in this study if they were 18 years or older at the start of the study, were still alive, and had a traceable postal address. Before the study began, 144 of the 470 patients had died (31%), 24 patients were younger than 18 years (5%), and 21 patients were untraceable (4%). The remaining 281 patients were eligible to participate. Of these patients, 173 returned the questionnaires (a response rate of 62%; see figure 1).

Socio-demographic data (age, gender, household composition, education, and employment status, use of alcohol or drugs), characteristics of the accident (traffic, at work, at home, sports, or attempted suicide), medical data (injury, duration of hospitalisation and intensive care unit (ICU) treatment, and treatment for psychological problems), and symptoms of different psychological problems (anxiety or depression, posttraumatic stress disorder, or subjective cognitive complaints) were collected.

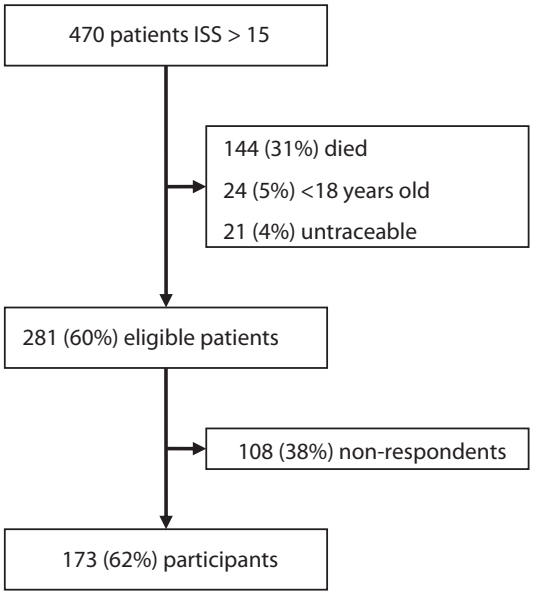

Figure 1. Flowchart of selection of eligible patients.

Instruments

Demographic data, characteristics of the accident and medical data were extracted from the regular trauma registry and a general questionnaire was designed to collect data on socio-demographics, the accident, and their health situation before the accident.

The abbreviated injury scale (AIS) and ISS, which are part of the regular trauma registry, were used to determine the injured body area and severity of the injuries. The AIS is anatomically based and classifies the severity of each injury by body region on a scale from 1 (minor) to 6 (non-survivable).[18] Injuries from all patients were coded prospectively, using the (AIS)-update 98. The ISS is calculated as the sum of the square of the AIS for the three most serious injuries in different ISS body regions. Individual-level overall injury severity scores range from 1 to 75.[19;20] Different studies have confirmed the validity of the ISS as a predictor of mortality.[21] The reliability of injury coding was found to be substantial and the reliability of the ISS almost perfect.[21;22] Only severely injured patients (ISS > 15) were included in this study, because an ISS of 16 is predictive of 10% mortality and defines major trauma based on anatomic injury. [23] Within the group severely injured patients a cut-off score of 25 is used, because a rapid increase in fatalities is seen when de ISS exceeds the value of 25.[24]

Several general questionnaires were used to determine different psychological complaints and the QOL of the participants after their rehabilitation phase.

The Hospital Anxiety and Depression Scale (HADS)[25] was used to screen for anxiety and depressive disorders. Both types of disorders are assessed with seven questions. The HADS has a 4-point response scale (0-3) and has been validated. The homogeneity and test-retest reliability of the total scale and the subscales are good (Cronbach's alpha: 0.84 for general medical patients).[26] The Cronbach's alphas in the current study were 0.83 for the subscale anxiety and 0.86 for the subscale depression. Subscale values ≥ 11 for one of the subgroups were regarded as a psychological complaint, as this cut-off score provides the lowest proportion of false positives (1% for depression and 5% for anxiety).[27]

The Dutch version of the Impact of Events Scale (IES; validated translation known as "Schokverwerkingslijst"[28]) was used as an indicator for PTSD. According to an examination of its psychometric properties, the questionnaire is reliable (Cronbach's alpha 0.95) and valid.[29] The Cronbach's alpha in the current study was 0.93. The IES consists of 15 items. Using a 4-point scale, the respondent states whether the content of each statement was present – 0 (not at all), 1 (rarely), 3 (sometimes), or 5 (often) - during the past seven days. A score of at least 35 represents the best cut-off for a probable diagnosis of PTSD.[30]

The Cognitive Failure Questionnaire (CFQ) was used to assess subjective cognitive complaints. The CFQ consists of 25 questions (with a 5-point response scale) about

memory deficits, absent-mindedness, or slips of action.[31] The questionnaire has been translated and found to be valid and reliable (Cronbach's alpha: 0.92).[32;33] The Cronbach's alpha for the current study was 0.95. Higher scores indicate more subjective cognitive complaints. The correlation between CFQ-scores and objective cognitive disorders is very weak, and scores on the CFQ reflect psychological well-being in the cognitive domain. Therefore, high CFQ-scores were considered to represent psychological complaints in the current study. Scores of 55 or higher indicate very low self-reported cognitive capacities.[33]

The Dutch version of the World Health Organization Quality of Life assessment instrument-BREF (WHOQOL-BREF) was used to measure QOL.[34;35] This instrument was used because it is a generic, cross-culturally developed comprehensive questionnaire that measures QOL as a person's subjective perceptions about his or her life with respect to goals, concerns, and satisfaction. The questionnaire consists of questions within the domains of 'physical health' (7), 'psychological health' (6), 'social relationships' (3), and 'environment' (8) and is supplemented with the domain 'general', which consists of two questions on QOL and general health. Each question has a 5-point response scale. The domain scores denote an individual's perception of the QOL in each particular domain and are scaled in a positive direction (i.e., higher scores denote higher QOL). The reliability and validity of the WHOQOL-BREF are good (Cronbach's alpha: physical health: 0.80, psychological health: 0.74, social relationships: 0.66, environment: 0.73).[36;37] In the current study the Cronbach's alphas are: 0.88 for physical health, 0.84 for psychological health, 0.65 for social relationships and 0.85 for environment, respectively. The domain values were calculated for each participant in the present study and compared with scores from a reference group of the Dutch general population with a mean age of 54 (SD 16) years old.[38]

When patients did not participate, they were called and asked for the reason and some basic information concerning their health status using a 3-point Likert scale from 'good' to 'not good at all'.

Procedures

Self-report questionnaires were sent by traditional post. The participants or their caregivers determined whether they were able to answer the questionnaires. The participants were included after written informed consent was obtained and if the questionnaires were completed and returned. The participants started with some socio-demographic questions, questions about their medication and physical and psychological situation before the accident, questions about the accident, and support after the accident. Subsequently, they were asked to complete the questions

of the WHOQOL-BREF, SVL, HADS, and CFQ and to return the set of questionnaires by traditional post. The questionnaires were completed between 15-53 months after their accident (mean time since injury 2.8 (SD 0.9) years). Data were entered in SPSS by a research assistant and checked on completeness and validity. Missing data were replaced with the participant's mean value on the corresponding subscale when one or two items were missing. If more data were missing from an assessment, the assessment was discarded.

Participants were considered to suffer from psychological complaints if they had a HADS score of at least 11 on one of the two subscales, an IES score of at least 35, or a CFQ score of at least 55.

Statistical analysis

To compare the group of non-respondents with the respondents, independent sample t-tests were used for continuous variables, and Chi-square tests were used for categorical variables. One-sample t-tests were employed to compare the QOL of polytraumatised patients with WHOQOL-BREF data from a Dutch reference group.[38] Chi-square tests were used to investigate the relationship between demographic, accident and injury characteristics and the presence of one of the psychological outcome parameters. Independent sample t-tests were used for continue variables.

Independent sample t-tests were performed to investigate the difference in QOL between participants with and without psychological complaints. The data were analysed using the IBM SPSS 19 statistical software (SPSS Chicago, IL, USA; version 19.0). The significance level was $p<0.05$ for all tests except the Chi-square tests. To take into account the number of tests, a significance level of $p<0.01$ was used for these Chi-square tests.

RESULTS

Participants' characteristics

Most participants were male and did not live alone. The mean age was 47 (SD 19) years, and most injuries were caused by traffic accidents. The most common injury was intracranial injury (61%). Serious intracranial injury (AIS>3) was present in 52% of the cases. The median ISS was 21 (interquartile range 17-27), and 86% of the participants had received ICU treatment. Participant characteristics are presented in table 1.

Ten participants indicated that they consumed more alcohol at present than they did prior to the accident. Only one of them drank more than 3 glasses of alcohol per day. Three participants declared that they used more drugs at present than they did before the accident. Two of these participants did not use drugs before the accident.

Table 1. Patient characteristics of severely injured patients.

Socio-demographic characteristics (*n*=173)	**category**	**n**	**%**
Age at start of the study	< 55	111	64%
	>=55	62	36%
Gender	Male	120	69%
	Female	53	31%
Education level*	Basic	33	19%
	Middle	86	50%
	High	44	25%
Household*	Alone	40	23%
	Together with*	131	76%
	Partner	55	32%
	Children	9	5%
	Partner and children	36	21%
	Parents	23	13%
	Students	3	2%
Employment at time of injury		113	65%
Returned to work after injury*		54	31%
Accident-related characteristics (*n*=173)		**n**	**%**
ISS	16 - 25	97	56%
	>=25	76	44%
Mechanism of accident	Blunt	166	96%
	Penetrating	7	4%
Type of accident*	Traffic	93	54%
	At home	33	19%
	At work	10	6%
	Sports	8	5%
	Raid	2	1%
	Attempted suicide	3	2%
	Other type of accident	23	13%
At least one injury in this AIS region	Head	131	76%
	Intracranial	105	61%
	Face	46	27%
	Thorax	71	41%
	Abdomen	30	17%
	Spine	38	22%
	Transverse myelitis	12	7%
	Upper extremity	53	31%
	Lower extremity	53	31%

Table 1. Continued.

Comorbidity before trauma (*n*=173)	n	%
Physical disorders*	43	25%
Treatment for psychological complaints*	16	10%
Medication for psychological disorders	13	8%
Medication use*	67	39%

*Category unknown: Education level: 10, Household: 2, Living together with: 5, Returned to work after injury: 4, Physical comorbidity: 1, Medication use: 4, Mental treatment: 1

The respondents and non-respondents did not differ significantly with respect to age, injured body area, severity of the injury, duration of hospitalisation, or ICU care. Although both groups mainly consisted of males, the females responded significantly more often than males based on a comparison of the respondent and the non-respondent group (31% vs. 15%; p=0.003).

Slightly more than half of the 108 non-respondents could be contacted by phone (n=56) to determine their health status and reason for not participating. Most of them were not interested (62%), and 14% did not want to be reminded of their accident or injury any more. For 16% of the patients, their health status was too bad to participate. One third of the contacted non-respondents declared that they did not feel well at all.

Psychological complaints

Sixteen persons of the investigated trauma population had psychological or psychiatric treatment before the accident. After the accident, 52 participants had psychological complaints. Ten of the 52 participants with psychological complaints after the accident also had psychological or psychiatric treatment before the accident. Twenty-one of the participants with psychological complaints after the accident suffered from two (11), three (6) or all four (4) investigated psychological problems. Most common was a combination of complaints of anxiousness with one of the other investigated psychological complaints. A combination of symptoms of PTSD and subjective cognitive complaints or symptoms of PTSD and depression almost only appeared in participants who also had additional psychological complaints. The frequencies of different types of psychological complaints are presented in table 2.

Regardless of the type of psychological complaint, approximately 50% of the participants with posttraumatic psychological complaints had not received psychological or psychiatric treatment after the accident. Thirty-seven participants received psychological counselling after their accident but no longer experienced psychological complaints.

Relationship between the psychological complaints and accident- and participant-related factors

Participants who were employed before the accident (p=0.001) and participants who resumed working after the accident (p<0.001) reported less psychological complaints. Use of medication before the accident (p=0.006) and treatment for psychological disorders before the accident (p=0.006) were positively related to the presence of psychological complaints. No significant association between any accident- or injury-related factor and the occurrence of psychological complaints was found (table 3). Psychological complaints were also unrelated to treatment-related factors, i.e., the time elapsed since the accident (p=0.389), the duration of hospitalisation (p=0.629), or duration of ICU treatment (p=0.760).

Psychological complaints and QOL

Participants with psychological complaints displayed worse QOL scores in all domains compared with those without psychological complaints (table 4) and compared with the Dutch reference population (see figure 2).

The QOL of participants without psychological complaints was not impaired compared with the reference population (see figure 2).

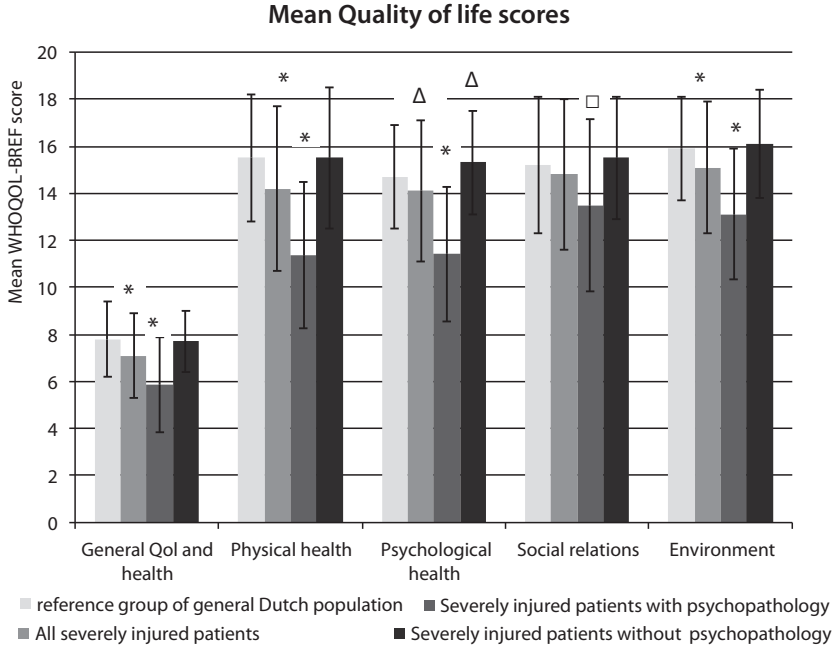

Figure 2. QOL scores of severely injured patients with and without psychological problems compared with a reference group of general Dutch population.
Δ $p < 0.05$, □ $p = 0.002$, * $p < 0.001$

Table 2. Number of severely injured patients with psychological complaints.

Mental treatment	Psychological problem				Participants with psychological problems*			
	Anxiety	Depression	PTSD	Cognitive complaints	Yes	No	Unknown	Total
Pre-traumatic only	5	4	1	2	5	2	1	8
Pre- and post- traumatic	2	3	2	4	5	3	0	8
Post-traumatic only	10	5	7	10	22	34	1	57
None	7	9	8	7	19	76	3	98
Unknown	0	0	1	0	1	0	1	2
Total	24	21	19	23	52	115	6	173
Percentage**	14%	12%	11%	13%	30%	67%	4%	100%

* Participants can have more than one psychological problem. Therefore, the number of participants with psychological problems is not equal to the sum of the participants within the different specified subgroups of psychological problems.
** Percentage of the 173 investigated participants.

Table 3. Frequencies, percentages and p-values of Chi-square test for demographic, accident-related and injury-related factors of severely injured patients.

		No psychological complaints n n (%)	Psychological complaints n (%)	p-value
Age at start of study	≥ 55	38 (23)	21 (13)	0.358
	< 55	77 (46)	31 (19)	
Gender	Male	86 (51)	30 (18)	0.026
	Female	29 (17)	22 (13)	
Housing situation at start of study	With others	89 (53)	39 (23)	0.735
	Alone	26 (16)	13 (8)	
Employment at time of injury	Yes	85 (51)	25 (15)	0.001*
	No	30 (18)	27 (16)	
Returned to work after injury**	Yes	51 (48)	3 (3)	<0.001*
	No	30 (28)	22 (21)	
ISS	≥ 25	49 (29)	25 (15)	0.510
	< 25	66 (40)	27 (16)	
Memories of accident	Yes	40 (25)	16 (10)	0.588
	No	72 (44)	35 (21)	
At least one injury in anatomic body region:	Head	86 (51)	40 (24)	0.766
	Face	28 (17)	17 (10)	0.260
	Thorax	47 (28)	21 (13)	0.953
	Abdomen	20 (12)	9 (5)	0.989
	Spine	23 (14)	13 (8)	0.467
	Upper extremity	34(20)	17 (10)	0.685
	Lower extremity	33 (20)	17 (10)	0.602
Physical disorders before injury	Yes	23 (14)	17 (10)	0.064
	No	92 (55)	34 (20)	
Treatment for psychological complaints before injury	Yes	5 (3)	10 (6)	0.006*†
	No	110 (66)	42 (25)	
Before injury medication for psychological disorders***	Yes	3 (20)	9 (60)	0.242†
	No	2 (13)	1 (7)	
Medication use before injury	Yes	35 (21)	28 (17)	0.006*
	No	77 (47)	24 (15)	

Result from crosstabs Chi-square:
* $p<0.05$, †Fisher exact
**Determined for participants with employment at time of injury
***Determined for participants with treatment for psychological problems before the injury

Table 4. QOL scores were decreased in all domains for severely injured patients with psychological complaints.

		WHOQOL-BREF				
	n	General QOL and health Mean ± SD	Physical health Mean ± SD	Psychological health Mean ± SD	Social relations Mean ± SD	Environment Mean ± SD
With psychological complaints	51	5.9 ± 2.0*	11.4 ± 3.1*	11.4 ± 2.9*	13.5 ± 2.7*	13.1 ± 2.8*
Without psychological complaints	113	7.7 ± 1.3	15.0 ± 3.0	15.3 ± 2.2	15.5 ± 2.6	16.1 ± 2.3

Student t-test; *$p<0.001$

DISCUSSION

The first objective of this study was to examine the incidence of psychological complaints among severely injured patients after the rehabilitation phase. Nearly 30% of the investigated participants had psychological complaints (anxiety (14%), depression (12%), PTSD (11%), and/or subjective cognitive complaints (13%)) 15-53 months after the accident. Several participants suffered from more than one psychological complaint. Previous studies found a higher degree of patients with psychological disorders after trauma, i.e., PTSD between 18% and 25% [39], [40], [23] and anxiety or depression between 25 and 39% [41;42] of the patients. This discrepancy may be due to different cut-off points, because we used conservative cut-off values in the current study, to find a low proportion of false positives for participants with psychological complaints. The discrepancy may also be caused by different procedures. In some former studies the assessments were conducted by a psychiatrist or trained clinical research assistants, whereas in our study the questionnaires were self-rated.

The second objective was to investigate the relationship between the psychological complaints and accident- and participant-related factors. We did not find an association between the injured body region and psychological complaints or between the severity of the injury (in terms of ISS) and the number of participants with psychological complaints. This result concurs with previous studies that did not find a relation between psychological outcome and head injury [43] or between the severity of injury and psychopathology.[6] However, Wallis et al. found more anxiety and depression in patients with a hand injury in a burn injury study, which could be caused by the high level of physical limitations, and accompanying dependency on other people's help that

is often the case with injured hands.[44]
The presence of psychological complaints seemed to be related to pre-accidental socio-demographic and health-related factors. In line with previous studies,[8], [45;46] females and patients who were unemployed or had psychological complaints before the accident more frequently reported psychological morbidity after rehabilitation. The use of any medication before the accident was related to psychological complaints after the accident. Remarkably, medication for psychological complaints before injury was not related to psychological complaints after the accident. This finding may be biased by the small number of patients with psychological complaints before the accident.
High prevalence of acute intoxication and chronic alcoholism in trauma patients were found in former studies, [47-49] and mental disease was found to be attributable to increased substance abuse. [50] However, we could not confirm these results in our study. The use of alcohol or drug may be underreported, because of the self-report method.
Survivors of a severe injury often have difficulties returning to work.[51;52] In accordance with previous studies,[40;50] return to work was related to the presence of psychological complaints after the accident. This association is important, as employment is an aspect of reintegration into society. In addition, disqualification from work causes high costs for society. Moreover, it may prolong psychological complaints leading to additional costs. However, this causality is unknown and should be investigated in a prospective study.
Approximately 50% of the participants with psychological complaints indicated that they had not received psychological counselling or social assistance after the accident. It is possible that the number of patients with psychological complaints and an impaired QOL after the injury would be lower if they had received more psychological support during treatment. Therefore, a higher awareness among hospital health care professionals is necessary to place greater emphasis on the involvement of psychological health care during the rehabilitation process of severely injured patients. Routine screening for psychological complaints would assist this awareness of appropriate psychological care.

The third objective was to investigate the relationship between the psychological complaints in severely injured patients and their QOL. Most previous studies investigated only HRQOL or only psychological complaints in trauma patients. In line with those studies,[1-4] we found a significantly decreased QOL of the severely injured patients compared to the general Dutch population in all domains except the social domain. The few studies that investigated HRQOL combined with psychological complaints after an injury, found an association between both factors.[3;53] We found similar results in patient experienced QOL. When we excluded participants with psychological complaints from the analysis, a difference with the Dutch general population was no longer

demonstrated. Thus, psychological morbidity appears not only to be an important factor in the decreased HRQOL, but also in the experienced QOL of severely injured patients after the rehabilitation phase.

Some important factors that were associated with psychological complaints after the rehabilitation phase, such as return to work and psychological treatment before the accident, are also known to be associated with (HR)QOL.[3;7] Although a previous study found that QOL was mainly related to living alone,[17] we did not find a relationship between household composition and the appearance of psychological disorders.

Several limitations should be mentioned. First, selection bias may be present, as the response rate was 62%. However, the group of non-respondents was similar to the group of respondents, except for a slight overrepresentation of women in the respondent group. Although gender did not affect QOL, women were found to suffer from psychological complaints more often than men. Moreover, many of the non-respondents indicated that they did not feel well at all, felt too unwell to participate, or did not want to be reminded of the accident. Therefore, the number of patients with psychological morbidity may be even higher and the QOL lower in the severely injured trauma population than was found in this study.

Second, recall bias may influence the current results. This problem is well-known in trauma care studies. Prospective documentation of patients' physical, psychological, and social well-being or health is impossible because it is not known who will experience an injury. To reduce recall bias, early documentation of health status is advisable. The patients were asked retrospectively for their pre-accident physical health and treatment for psychological complaints. The number of participants in the study that indicated that they had treatment for psychological complaints before the accident (9%) was similar to the number of patients with pre-existing psychological disturbance found in a previous study (11%).[5]

Third, we compared the present data with data from a reference group of the Dutch general population, of which the incidence of psychological complaints is unknown. Future studies should incorporate a healthy control group.

Finally, the total number of participants was insufficient for subgroup analysis, and a follow-up was not possible due to the cross-sectional study design. Future studies should include prospective follow-up studies with larger samples. The relationship with physical impairment should also be taken into account.

CONCLUSION

To our knowledge, this is the first study to show that QOL may only be impaired in the severely injured patients who suffer from psychological complaints. One third of the participants suffered from psychological complaints 15-53 months after their accident, and only half of them received psychological counselling. Pre-accident mental treatment and inability to return to work (social reintegration) may be risk factors for psychological complaints. It seems that the need for psychological treatment remains underestimated after a severe trauma. Therefore, greater attention should be paid to psychological complaints in severely injured patients during treatment, and routine screening for these complaints may be warranted.

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CHAPTER 4

Psychometric properties of the Dutch Short Musculoskeletal Function Assessment (SMFA) questionnaire in severely injured patients

C.C.H.M. van Delft-Schreurs
M.A.C. van Son
M.A.C. de Jongh
T. Gosens
M.H.J. Verhofstad
J. de Vries

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ABSTRACT

Purpose

In this cross-sectional study the psychometric properties are examined of the adapted Dutch translation of the Short Musculoskeletal Function Assessment (SMFA) questionnaire in severely injured patients (ISS>15).

Methods

Patients (N = 173) completed the SMFA, the World Health Organization Quality of Life assessment instrument-BREF (WHOQOL-BREF), the Dutch Impact of Event Scale (IES), the Hospital Anxiety and Depression Scale (HADS) and the Cognitive Failure Questionnaire (CFQ). The Abbreviated Injury Score and the Injury Severity Score were established to determine the injured body area and the severity of the injuries. Exploratory factor analysis (method: PAF) was performed. Correlations were calculated between our SMFA factors and scores on the WHOQOL-BREF, IES, HADS and CFQ. The SMFA scores of the factors Upper and Lower were compared between subgroups of patients with and without injuries in respectively the upper extremities and the lower extremities. For responsiveness analysis, data were compared with the baseline SMFA measurement of a reference group.

Results

A three-factor structure was found: Lower extremity dysfunction, Upper extremity dysfunction, and Emotion. Strong correlations between the SMFA and the other questionnaires were found. Patients with injury of the lower extremities had significantly higher scores on the factor Lower extremity dysfunction than patients without injury of the lower extremities ($p=0.017$). In none of the factors, a significant difference in mean scores was found between patients with and without injury of the upper extremities. Severely injured patients had significantly higher SMFA scores than the reference group ($p<0.001$).

Conclusions

The adapted Dutch translation of the SMFA showed good psychometric properties in severely injured patients. It appeared to be useful to get a general overview of patients' health status (HS) as well as patients' quality of life (QOL).

INTRODUCTION

Patients who survive a severe injury often have several types of long lasting disabilities. This often has serious social and economic consequences.[1] This is not only caused by objective functional limitations. Subjective factors seem to be involved in the recovery process as well. So it is relevant to pay also attention to the patients' experiences about their functioning. For this purpose, health status (HS) and health related quality of life (HRQOL) questionnaires have been designed. In HS studies patients are asked about their experiences concerning functioning on a physical, psychological and social domain. (HR)QOL studies, have added the factor satisfaction with this functioning to this concept.

There is a growing interest to investigate HS and HRQOL of severely injured trauma survivors, but it is difficult to examine this adequately in those patients with body region specific questionnaires, because they often have injuries in multiple body regions. Therefore, generic questionnaires, like the EuroQol Group's EQ-5D instrument (EQ-5D) and the Short-Form-36 (SF-36), are mostly used to measure HS in severely injured patients.

However, HS questionnaires like the EQ-5D and the SF-36 have been designed to examine limitations concerning functioning. No attention is paid to patients' satisfaction with functioning, although this is the core of the definition of QOL according to the World Health Organization Quality of Life Group (WHOQOL group).[2] The Short Musculoskeletal Function Assessment (SMFA), a generic questionnaire that is also frequently used to determine functional limitations, pays attention to HRQOL. It has been designed to measure the HS and HRQOL of patients with a broad range of musculoskeletal injuries and disorders and consists of two parts: a functional index and a bothersome index. The bothersome index, in which patients are asked how much they are bothered by their physical limitations, pays attention to the aspect satisfaction with functioning. Therefore, we used the SMFA as part of a larger study in which the (HR)QOL of severely injured patients was investigated.[3;4] In the questions of the functional index, patients are asked for their physical limitations. This index is grouped into four categories: daily activities, emotional status, function of arm and hand, and mobility.[5]

The SMFA has been translated in several languages and found to be valid in several studies. However, in the studies in which a factor analysis was performed, the properties of the translated SMFA did not meet original a priori the structure of the conventional Function and Bother index.[6-9]

In addition, the SMFA has not yet been examined in severely injured patients (ISS>15), a trauma population that often suffers from multiple injuries including brain injury.

Moreover, because this concerns a specific subpopulation of trauma patients, those patients were excluded in some former SMFA validation studies.[5;9]
Furthermore, former validation studies were focused on HS[7-9] instead of (HR)QOL.

The purpose of this study was to examine the structure and psychometric properties of the adapted Dutch translation of the SMFA questionnaire in severely injured patients.[6] We hypothesized that the Dutch translation of the SMFA was valid in our study population and that it measured HS with the Function index and HRQOL with the Bother index.

PATIENTS AND METHODS

Patients

A retrospective cohort of severely injured patients (Injury Severity Score (ISS) >15), who were hospitalized in the St. Elisabeth Hospital (Tilburg, The Netherlands) between 2006 and 2009 could take part in this cross-sectional study. The patients were asked to participate if they were 18 years or older at the start of the study, still alive, had a traceable postal address and were able to answer a questionnaire set in Dutch, that was sent by postal mail in 2010. The patients were included if the questionnaires were completed and returned and written informed consent was obtained.

Measures

The AIS 1990 update 98[10] and ISS were used to determine the injured body region and severity of the injuries. The AIS classifies each injury by body region on a scale from 1 (minor) to 6 (non-survivable).[10] The ISS is the sum of the square of the AIS for the most serious injuries in three different ISS body regions and yields scores for the overall severity of the injury from 1 to 75.[11;12]
The patients were divided into seven subgroups based on the Abbreviated Injury Scale (AIS) and ISS. The first two groups consisted of patients with an injury of the upper or the lower extremities, respectively, regardless of the severity of those injuries or concomitant injuries. Within these two groups, patients with isolated injury of the upper or lower extremities were at least considered to have an injury with a moderate severity (AIS .2) in the upper or lower extremities respectively, and no severe injuries (AIS ≤ .3) in other body regions. Besides, two groups consisted of patients without an injury of the upper of lower extremities, regardless of the severity of the injuries or concomitant injuries.
In addition, three groups were defined to investigate the difference in scores between patients with and without brain injury. Patients with isolated brain injury were defined as patients with at least a serious injury (AIS > .2) of the internal organs of the head.

Patients with brain injury combined with other injuries had complementary injuries in other body regions. Patients without brain injury had no serious injury (AIS > .2) of the internal organs of the head.

Questionnaires

A general questionnaire consisting of questions on socio-demographics and the accident had to be completed. Demographic data (age, gender, household composition, education, being at work), characteristics of the accident (traffic, at work, at home, sports, attempted suicide), and medical data (injury, duration of hospitalization and ICU treatment) were extracted from the trauma registry.

SMFA

The SMFA, designed to assess HS and HRQOL of patients with a broad range of musculoskeletal injuries and disorders, had been translated in an earlier study and six double-barrelled items of the American English SMFA[5] had been divided into two separate questions.[6] After these adaptations, the Function index contained 39 items and the Bother index 14 items. Both indices use a five-point Likert scale with scores ranging from 1 (not at all/never/none) to 5 (unable to do/always/extremely). After summing the responses and score transformation according to the original American English SMFA[5], the indices range from 0 to 100. Higher scores indicate a lower HS and lower HRQOL. The adapted Dutch version of the SMFA has been validated in patients with a fracture in the upper or lower extremity.[6]

Quality of life

The Dutch version of the World Health Organization Quality of Life assessment instrument-BREF (WHOQOL-BREF) was used to measure quality of life (QOL).[13;14] It consists of two questions about QOL and general health and 24 questions within the domains Physical health (7), Psychological health (6), Social relationships (3), and Environment (8). Each question has a five-point response scale. The domain scores indicate an individual's perception of their QOL in each particular domain. Higher scores indicate a higher QOL. The reliability and validity of the WHOQOL-BREF are good.[15;16]

Psychological problems

The Hospital Anxiety and Depression Scale (HADS)[17] was used to screen for anxiety (7 questions) and depressive symptoms (7 questions). The HADS has a four-point response scale (0-3) and has been validated. The homogeneity and test-retest reliability of the total scale and the subscales are good.[18]

The Dutch version of the Impact of Events Scale (IES)[19] was used as an indicator for a post-traumatic stress disorder (PTSD). Psychometric properties have been examined and the questionnaire proved reliable and valid.[20] The IES consists of 15 items. For every statement, the respondent answers on a 4-point scale whether this was present – with 0 (not at all), 1 (rarely), 3 (sometimes), or 5 (often) - during the past seven days.

The Cognitive Failure Questionnaire (CFQ) was used to assess subjective cognitive complaints. The CFQ is a questionnaire with 25 questions about deficits in memory, absent-mindedness, or slips of action and it has a 5-point response scale.[21] The questionnaire has been translated and found to be valid.[22]

Statistical analysis

Independent sample t-tests were used for continuous variables and Chi-square tests for categorical variables to compare the group of non-respondents with the respondents.
Exploratory factor analysis (method principal axis factoring (PAF)) with oblique rotation was used to analyze the underlying factor structure of the adapted SMFA. Suitability for PAF was assessed with the Kaiser–Meyer–Olkin measure, with 0.5 being the minimum acceptable value, and with Bartlett's test of sphericity. Kaiser's criterion and Cattell's scree plot were used to extract the number of factors. An iterative process was performed in which items with factor loadings with less than 0.2 differences between the three different factors were removed during initial iterative process. During the latter steps of this process factors with a difference less than 0.1 between two factors were removed. Cronbach's alpha coefficients (α) were calculated for each newly identified factor. An alpha of at least 0.70 was considered acceptable. Floor and ceiling effects were determined and values of skewness and kurtosis were calculated to get an indication for violation of the normality assumption.
Because of violation of the normality assumption, non-parametric tests were performed to calculate the correlation coefficients (rho) between the SMFA factors, WHOQOL-BREF domains, HADS, IES and CFQ. For responsiveness analysis, data were compared with baseline SMFA values of a reference group with a non-parametric Mann-Whitney U test. To determine responsiveness, baseline values from 351 patients who had clearly been instructed to provide their pre-injury scores in a former study[6], were used as a reference group. The mean factor values of this group were compared with the mean values of the severely injured patients.
The age and gender of the reference group and the severely injured patients were compared with an independent sample t-test and a Chi-square test, respectively. Besides, SMFA scores of the factors Upper extremity dysfunction and Lower extremity dysfunction were compared between subgroups of patients with and without injuries in

respectively the upper extremities and the lower extremities with non-parametric tests. An ANOVA was performed to determine whether a difference in the SMFA scores of new factors could be determined in subgroups of patients with isolated brain injury, patients with brain injury combined with other injuries and patients without brain injury.
The data were analyzed using IBM SPSS statistics 19 software (SPSS Chicago, IL, USA; version 19.0). The significance level was 0.05 for all of the tests used.

RESULTS

Characteristics of the patients

Patient selection has been described extensively elsewhere.[3;4] Briefly, 173 severely injured patients (response rate: 62%) returned the questionnaires between 1.3 and 4.4 years after the injury.
Most patients were males (69%), with a mean age of 46 (SD 19) years, and a median ISS of 21. The most common injury was intracranial injury (61%). Those patients were divided in two groups: patients with isolated brain injury (68 patients) and patients with brain injury combined with other injuries (37 patients). Serious intracranial injury (AIS>3) was present in 52% of the cases. Ten patients had isolated injury of the upper extremities and 18 patients had isolated injury of the lower extremities.

Dimensionality

Results from the Kaiser-Meyer-Olkin measure (0.903) and Bartlett's test of sphericity showed that data were appropriate for exploratory factor analysis (table 1).
The three-factor solution (R^2 = 64%) was most interpretable. Seventeen items (5, 6, 9, 10, 15, 17, 18, 22, 24, 26, 28, 32, 33, 40, 44, 45 and 46) have been removed during the iteration process. The factor analyses resulted in the following three factors 1: Lower extremity dysfunction (15 items); factor 2: Upper extremity dysfunction (11 items) and factor 3: Emotion (10 items). Table 2 presents the factor loadings. Cronbach alphas were > 0.90 for the three factors (see table 3).

Score distribution and missing data

The assumption of normality was violated for the factor Upper extremity dysfunction. Ceiling scores were present in 43% of the patients for the factor Upper extremity dysfunction. For the other components no notable floor and ceiling effects were found (see table 3).
Overall, the percentage of missing data ranged from 1.7 to 10.4%. Sixteen patients did not return the last page of the questionnaires. Apart from those missing values, questions about sexual activity, questions about activities for which use of lower

extremities is required, such as kneeling down, getting up, using the legs or the back, and questions about working, sporting and doing chores around home were missing most often (6-8 times).

Table 1. Factor extraction: principal axis factoring.

Indices for factor extraction	
Kaiser–Meyer–Olkin measure	0.903
Bartlett's test of sphericity	$\chi 2 = 7272.36$, $p<.0001$
Principal component analysis	Seven factors ($R^2 = 74.1$ %)
Cattell's scree plot	Three factor solution
Items removed during iterative process	17 items

Table 2. Factor loadings in a three-factor solution for severely injured patients.

	Upper extremity dysfunction	lower extremity dysfunction	Emotion
Difficulty to:…			
1 Get in or out a low chair	0.406	**0.735**	
2 Open bottles[a]	**0.695**	0.352	
3 Open jars[a]	**0.698**	0.349	
4 Shop groceries	**0.639**	0.355	0.380
7 Make a fist	**0.661**		
8 Use the bath, tub or shower	**0.733**	0.483	
11 Kneel down[a]	0.411	**0.696**	
12 Use buttons or zippers	**0.826**		
13 Cut own fingernails	**0.771**		
14 Get dressed	**0.731**	0.436	
16 Move after sitting or lying down	0.324	**0.778**	
19 Clean yourself after going to the bathroom	**0.773**	0.346	
20 Turn knobs or levers	**0.760**		
21 Write or type	**0.636**		0.310
23 Do your physical recreational activities	0.410	**0.630**	
25 Be sexual active	0.450	**0.611**	
27 Do heavy housework	0.461	**0.682**	0.325

Table 2. Continued.

	Upper extremity dysfunction	lower extremity dysfunction	Emotion
Frequency…			
29 Walk with a limp	0.353	**0.741**	
30 Avoid using painful limb[a]		**0.750**	
31 Avoid using your back[a]		**0.663**	
34 Problems with concentration			**0.677**
35 Doing too much one day affecting what you do the next day			**0.619**
36 Acting irritated towards those around you			**0.691**
37 Being tired			**0.652**
38 Feeling disabled		**0.628**	0.430
39 Feeling angry or frustrated because of injury			**0.702**
Bothered by…			
41 Problems using legs[a]	0.345	**0.761**	
42 Problems using back		**0.729**	
43 Problems doing chores in and around home	0.423	**0.660**	0.404
47 Problems with important people in your life			**0.636**
48 Problems with thinking, concentration, or remembering			**0.689**
49 Problems coping with your injury or signs of wear		0.448	**0.678**
50 Problems doing usual work		0.443	**0.601**
51 Problems feeling dependent on others		0.375	**0.604**
52 Problems with stiffness[a]		**0.760**	0.396
53 Pain[a]		**0.642**	0.481

Substantial (>0.6) factor loadings are marked bold.
Removed items with no substantial difference in factor loadings between the different factors during iterative process (items: 5, 6, 9, 10, 15, 17, 18, 22, 24, 26, 28, 32, 33, 40, 44, 45 and 46. They had a difference < 0.2 between the three factors in initial iteration process or a difference < 0.1 for two factors).
a = The original SMFA questions 2, 8, 27, 28, 35, 46 were divided into two questions.

Table 3. Descriptive statistics: mean SMFA scores (SD), skewness, kurtosis, floor and ceiling effects and internal consistency/reliability.

SMFA	Mean (SD) Skewness; kurtosis	Floor score %	Ceiling score %	Reliability Cronbach's alpha
Upper extremity dysfunction (*n*=164; 11 items)	12.1 (20.2) 2.263; 5.053	0.6	43.3	0.93
Lower extremity dysfunction (*n*=131; 15 items)	26.6 (24.9) 0.870; -0.271	0	9.2	0.96
Emotion (*n*=145; 10 items)	33.9 (20.9) 0.428; -0.518	0	2.8	0.90

Validity

Correlation coefficients are shown in table 4. High correlations were found between the SMFA factors Lower extremity dysfunction and Upper extremity dysfunction with the WHOQOL-BREF Physical health domain (r = 0.70 & r = 0.58, respectively). High correlations were also found between the SMFA factor Emotion and the HADS, CFQ and all WHOQOL-BREF domains, except for the domain Social relationship. The IES showed low correlations with the factors Upper extremity dysfunction and Lower extremity dysfunction.

When comparing patients with and without injury of the lower extremities, only significant higher scores were found in the factor Lower extremity dysfunction for patients with injury of the lower extremities. In none of the factors, a significant difference in mean scores was found between patients with and without injury of the upper extremities (see table 5).

Patients with brain injury indicated lower SMFA scores for the factors Upper extremity dysfunction and Lower extremity dysfunction, and higher SMFA scores for the factor Emotion than patients with other injuries (see figure 1). No significant difference in mean SMFA scores was found for patients with or without brain injury.

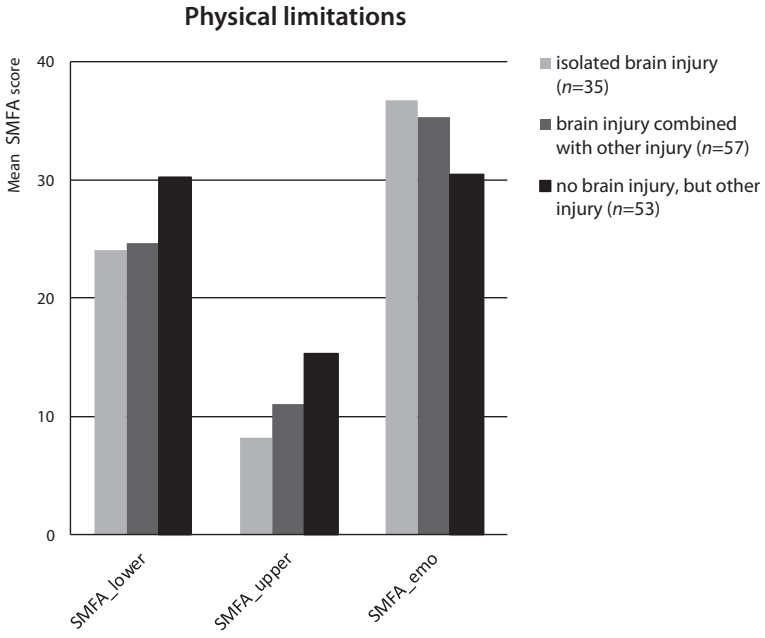

Figure 1. Comparison of the mean SMFA scores of the new SMFA factors for subgroups of severely injured patients with different injuries. Higher scores indicate more problems.

Table 4. Spearman's correlation coefficients between SMFA subscales, WHOQOL-BREF domains, IES, HADS and CFQ.

	Lower extremity dysfunction		Upper extremity dysfunction		Emotion	
	r	p-value	r	p-value	r	p-value
WHOQOL-BREF						
General	-0.540	< 0.001	-0.371	< 0.001	-0.635	< 0.001
Physical health	-0.700	< 0.001	-0.576	< 0.001	-0.769	< 0.001
Psychological health	-0.514	< 0.001	-0.429	< 0.001	-0.690	< 0.001
Social relationships	-0.306	< 0.001	-0.245	0.002	-0.361	< 0.001
Environment	-0.531	< 0.001	-0.415	< 0.001	-0.614	< 0.001
IES	0.231	0.008	0.217	0.006	0.330	< 0.001
IES intrusion	0.255	0.003	0.244	0.002	0.351	< 0.001
IES avoidance	0.206	0.019	0.184	0.020	0.310	< 0.001
HADS						
HADS anxiety	0.323	< 0.001	0.265	0.001	0.600	< 0.001
HADS depression	0.559	< 0.001	0.476	< 0.001	0.704	< 0.001
CFQ	0.370	0.004	0.373	< 0.001	0.688	< 0.001

SMFA Short Musculoskeletal Function Assessment questionnaire, WHOQOL-BREF World Health Organization Quality of Life assessment instrument-BREF, IES Impact of Events Scale, HADS Hospital Anxiety and Depression Scale, CFQ Cognitive Failure Questionnaire, r Spearman's rho correlation coefficient.

Responsiveness

Mean SMFA scores of the severely injured patients were significantly higher compared to baseline scores of the reference group for all new factors (see table 5). The reference group did not significantly differ from the group of severely injured patients with regard to age. There were significantly more males ($p<0.001$) among the severely injured patients (69%) than in the reference group (43%).

Table 5. Mean SMFA scores, standard deviations and number of patients for the whole study population, different subgroups and a reference group.

	SMFA					
	Baseline score of patients before their accident* Mean (SD); n	**Whole study population Mean (SD); n**	**Patients with injury of upper extremities Mean (SD); n**	**Patients without injury of upper extremities Mean (SD); n**	**Patients with injury of lower extremities Mean (SD); n**	**Patients without injury of lower extremities Mean (SD); n**
Upper extremity dysfunction	7.4 (16.6); 310	12.1 (20.2); 164	12.3 (19.2); 50	12.0 (20.8); 114	12.0 (17.7); 49	12.2 (21.3); 115
Lower extremity dysfunction	15.7 (19.4); 288	26.6 (24.9); 131	30.1(25.3); 40	25.0 (24.7); 91	35.7 (27.5); 38	22.8 (22.9); 93**
Emotion	20.3 (15.9); 300	33.9 (20.9); 145	37.6 (20.9); 43	32.3 (20.8); 102	33.6 (20.4); 42	34.0 (21.3); 103

*Data from a former validation study in which patients were clearly instructed to provide pre-injury SMFA scores.[6] This group had a significantly lower mean SMFA score than the whole study population for all factors (non-parametric Mann-Whitney U-test: $p<0.001$)

**Comparing patients with and without injury of the lower extremities with a non-parametric Mann-Whitney U-test resulted only in a significant mean difference for the factor SMFA lower extremity dysfunction ($p=0.017$).

DISCUSSION

The aim of this study was to examine the structure and psychometric properties of the adapted Dutch translation of the SMFA questionnaire[6] in severely injured patients.
A three-factor structure, with the factors Upper extremity dysfunction, Lower extremity dysfunction and Emotion, seemed to fit the data best. Furthermore, our adapted and translated Dutch SMFA was shortened with 17 items, which had no substantial factor loadings. Reininga *et al*. (2011), who excluded patients with brain injury, found a four factor structure.[9] Next to the factor Problems with daily activities, they also found the factors Upper extremity dysfunction, Lower extremity dysfunction and Mental and emotional problems. Our result is in agreement with the structure that was found in the three other studies in which the structure of a translated SMFA was determined.[6-8] They all found a three factor structure with, on the one hand, the more functioning related factors Lower extremity dysfunction and Upper extremity dysfunction and, on the other hand, a HRQOL related factor named: Daily life consequences, Lifestyle alterations or Bother. A future study should repeat the same factor analysis in another dataset with SMFA scores of severely injured patients to further validate the three factor structure.
Van Son *et al.* (2014), who validated the Dutch version of the SMFA in patients with an isolated fracture of the upper or lower extremity, found similar factors as found in the present study[6]. Because the patients in that study could not be regarded as a homogenous group, it was suggested to develop separate SMFA modules for those groups. However, especially in the factors Upper extremity dysfunction and Emotion we found the same factors and even more or less the same questions per factor in our patient population with mixed injuries. So, we assume that our structure could be suitable for patients with isolated injury of upper or lower extremities as well. However, this should be investigated further.

To investigate the clinical relevance, the SMFA-scores of the three factors were compared with scores on several other questionnaires in different groups of patients. A high correlation between the factor Emotion and the scores of the WHOQOL-BREF, HADS and CFQ verified the factor Emotion. The correlation between de factor Emotion and the IES was quite low. This may be due to the fact that the questions in the IES are referred to experiences of the accident that happened 1.3 - 4.4 years ago. The other questionnaires had a short reference time. Thus, those questionnaires are probably more related to their lives after the accident and less related to feelings about the accident itself. Therefore, the way of thinking about the accident seems not really important for the experience of their living situation after the accident. However, this should be investigated further.

High correlations between the factors Upper extremity dysfunction and Lower extremity dysfunction, and the Physical domain of the WHOQOL-BREF supported those factors. Severely injured patients seldom suffer from isolated injuries and often have brain injuries. Therefore, for this patient population no gold standard was available for comparison of the SMFA-scores with physical limitation scores of other questionnaires. Therefore, the differences in the mean SMFA scores of patients with and without injury of the upper extremities or with and without injury of the lower extremities were compared with each other for the factors Upper extremity dysfunction and Lower extremity dysfunction. Since most patients had injuries in several body regions, there were only few patients with isolated injury of the upper or lower extremities. Unless the low number of patients with isolated injuries of the lower extremities (18 patients), significant higher scores of the factor Lower extremity dysfunction in patients with injury of the lower extremities were found. This grounds the clinical relevance of the factor Lower extremity dysfunction. No significant mean scores were found between patients with and without injury of the upper extremities. This can be due to the even lower number of patients with isolated injury of the upper extremities (10 patients). Besides, the SMFA measurement was performed quite a long time after the injury. Patients might therefore already have been completely recovered from some of their injuries. A ceiling effect was found for the factor Upper extremity dysfunction, which supports this assumption for patients with injuries of the upper extremities.
In addition, long term physical limitations could be due to brain injury in severely injured patients. Half of the patients in the study population had brain injury. Therefore, these patients were compared with patients without brain injury. Patients with brain injury indicated lower SMFA scores for the factors Upper and Lower extremity dysfunction, and higher SMFA scores for the factor Emotion than patients without brain injuries. So patients with brain injury seem to suffer less from their physical limitations and experience more emotional problems, compared to polytraumatized patients without brain injury. Those differences were not found to be significant. This might be due to the small patient groups. However, because sequelae of severe brain injury could influence the SMFA scores, the exclusion of those patients, which occurred in some former studies,[5;9] could be considered. As this concerns a large part of the severely injured patients, it might be better to include the patients and perform separate analyses for this group.

We expected that the Bother index would be highly related with the WHOQOL-BREF. In former validation studies, the SMFA showed high correlations with questionnaires measuring HS, like the SF-36. This study was the first to compare the SMFA with a QOL questionnaire.

Because the factor analysis revealed other factors than the Function index and the Bother index, the new factors were compared with the WHOQOL-BREF. The factor Emotion showed the highest correlation with all domains of the WHOQOL-BREF. This was as expected, because half of the questions in the factor Emotion were derived from the conventional Bother index, and none of the questions was directly related to the actual physical limitations. Although half of the questions were derived from the conventional Function index, those questions were all related to the frequency of occurrence of problems with concentration and feelings that may have to do with the actual physical limitations.
Because the correlation between the factor Emotion and the domain Social relationships was low, social relations seem to be a less important factor for patients psychological health in severely injured patients. This should be investigated further.
The factor Lower extremity dysfunction was also expected to measure QOL, because one third of the questions of this factor was revealed from the conventional Bother index. This was indeed reflected in the high correlation coefficient between the factor Lower extremity dysfunction and the domain Physical health of the WHOQOL-BREF. So, QOL is not only measured in the SMFA factor Emotion, but also taken into account in the factor Lower extremity dysfunction. The correlation between the factor Upper extremity dysfunction and the Physical domain of the WHOQOL-BREF is good, although it is, as expected, lower than for the factors Lower extremity dysfunction and Emotion. If future studies aim to also measure QOL, it may be worth considering using the SMFA instead of a HS questionnaire.

Concerning responsiveness, no baseline values of the multiple injured study population were available. Such data are very difficult to achieve prospectively, since severely injured patients frequently are sedated a long time or communication is unreliable or impossible due to the trauma itself. The patients in this study were retrospectively asked to participate and could therefore only be asked for their current SMFA scores. Baseline scores of not multiple injured patients from a former validation study[6] were used as comparison. The trauma population of severely injured patients might be slightly different from that population, but their baseline scores are presumably comparable to pre-injury scores of patients who became less severely injured with a comparable age. Unless the quite long time that had already elapsed after the accidents and the high ceiling effect for the factor Upper extremity dysfunction, the SMFA scores of the injured patients were increased for all factors compared to the scores of this reference group. Responsiveness therefore seems to be warranted.
The adapted SMFA was found to be a valid and reliable measure in severely injured patients. Besides, the questionnaire seems to pay attention to perceived QOL as well, since high correlations were found between the three factors of the SMFA and

corresponding domains of the WHOQOL-BREF. So the adapted SMFA appears to be useful to get a general overview of patients' HS as well as patients' QOL.

Limitations

No test-retest reliability was performed in this study. However, this has been performed with the same questionnaire in a former study and was found to be good.[6]

The EQ-5D and the SF-36 have frequently been used for comparison with SMFA-scores in former validation studies.[5-9] Because our study focused on QOL, the scores of the WHOQOL-BREF domains, and some psychological questionnaires were used for comparison. The same Dutch translation of the SMFA questionnaire has been compared with the physical related RAND 36-item Health Survey (RAND-36) subscales, a questionnaire almost equal to the SF-36[23], in a former validation study in patients with an isolated upper or lower extremity fracture. The questionnaire was found to be valid in those populations.[6]

Answers of the last ten questions of the conventional Bother index were missing in 12 patients. We assume that they accidentally did not receive the page with these questions, since they did return the other pages of the questionnaires. No multiple imputations were performed, since we needed to examine the relation between the provided answers to say something about the questionnaire itself. Thus imputing is undesirable for a validation study. Besides, these missing values are randomly spread among the study population.

CONCLUSION

In agreement with results of some previous validation studies in other study populations, this Dutch version of the SMFA showed that a three factor solution seems to be a better solution in severely injured patients than the conventional bifocal index and that some questions could be omitted. The adapted Dutch translation of the SMFA with the factors Upper extremity dysfunction, Lower extremity dysfunction and Emotion showed good psychometric properties in severely injured patients and the factors were highly correlated with the corresponding domains of the WHOQOL-BREF.

The adapted Dutch SMFA seems to be valid and useful to get a general overview of physical limitations and emotional problems of the group of severely injured patients.

It may be relevant to analyze SMFA-scores from patients with traumatic brain injury separately from patients without brain injury. However, this should be further investigated.

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CHAPTER 5

The relationship between physical and psychological complaints and quality of life in severely injured patients

C.C.H.M. van Delft-Schreurs
M.A.C. van Son
M.A.C. de Jongh
K.W.W. Lansink
J. de Vries
M.H.J. Verhofstad

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ABSTRACT

Purpose

The purpose of this study was two-fold. The first goal was to investigate which variables were associated with the remaining physical limitations of severely injured patients after the initial rehabilitation phase. Second, we investigated whether physical limitations were attributable to the association between psychological complaints and quality of life in this patient group.

Method

Patients who were 18 years or older and who had an injury severity score (ISS) > 15 completed a set of questionnaires at one time-point after their rehabilitation phase (15-53 months after their trauma). The Short Musculoskeletal Function Assessment (SMFA) questionnaire was used to determine physical limitations. The Hospital Anxiety and Depression Scale, the Dutch Impact of Event Scale and the Cognitive Failure Questionnaire were used to determine psychological complaints, and the World Health Organization Quality of Life assessment instrument-BREF was used to measure general Quality of Life (QOL).

Differences in physical limitations were investigated for several trauma- and patient-related variables using non-parametric independent-sample Mann-Whitney U tests. Multiple linear regression was performed to investigate whether the decreased QOL of severely injured patients with psychological complaints could be explained by their physical limitations.

Results

Older patients, patients with physical complaints before the injury, patients with higher ISS scores, and patients who had an injury of the spine or of the lower extremities reported significantly more physical problems. Additionally, patients with a low education level, patients who were living alone, and those who were unemployed reported significantly more long-term physical problems.

Severely injured patients without psychological complaints reported significantly less physical limitations than those with psychological complaints. The SMFA factor of Lower extremity dysfunction was a confounder of the association between psychological complaints and QOL in all QOL domains.

Conclusions

Long-term physical limitations were mainly reported by patients with psychological complaints. The decreased QOL of severely injured patients with psychological

complaints can partially be explained by physical limitations, particularly those involving lower extremity function. Experienced physical limitations were significantly different for some trauma and patient characteristics. These characteristics may be used to select patients for whom a rehabilitation programme would be useful.

INTRODUCTION

Survival from trauma has increased in recent decades.[1] Therefore, the focus is shifting from mortality to non-fatal outcome parameters, such as (health-related) quality of life ((HR)QOL). Previous studies showed that the (HR)QOL of severely injured patients is lower than that of the general population.[2-8] This decrease in (HR)QOL seems to depend on both psychological complaints and physical limitations, but few studies measured these three parameters within the same study population.

Severely injured patients can suffer from long-lasting physical disabilities.[9-12] A strong association was found between these physical limitations and (HR)QOL.[13-15] To improve the (HR)QOL of patients with physical limitations, it is important to gain more insight into factors that are associated with the long-lasting physical limitations of trauma survivors.

In addition, psychological problems in trauma survivors were shown to be an important and possibly underestimated factor for their decreased (HR)QOL.[16-20] It is known that traumatic experiences such as a life-threatening experience or a severe accident can cause psychological problems, such as anxiety, depression, or posttraumatic stress disorder (PTSD). The patients who develop these symptoms may be more bothered by similar physical complaints than the patients without psychological problems. An association between impaired functional outcome and post-traumatic psychological complaints has been described.[20-23] Therefore, psychological complaints may be caused by the physical sequelae of severely injured patients and cause a decreased QOL in trauma survivors as a result. However, as far as we know, this has not previously been investigated. Therefore, we assessed physical functioning, psychological complaints and QOL of severely injured patients after their rehabilitation phase. Strong correlations between psychological complaints and QOL and between physical limitations and QOL have already been determined in this study population.[13;18] The time between the trauma and the completion of the questionnaires neither significantly influenced the OQL nor the psychological complaints of this patient group.[18;24]

The first objective of this study was to examine the relationship between the physical functioning of severely injured patients after their first rehabilitation phase and injury- or patient-related factors. The second objective was to determine whether the decreased QOL associated with psychological complaints could be explained by the physical limitations of these patients. If their decreased QOL was mainly caused by psychological complaints, then psychological interventions would be a good foundation to improve the QOL of severely injured patients.

PATIENTS AND METHODS

Inclusion criteria and the methods for data collection are described briefly here because they have previously been extensively described.[18;24] Patients who were hospitalized because of a severe injury (ISS >15) were included in this cross-sectional study if they were 18 years of age or older, had a traceable home address, were able to complete a set of questionnaires in Dutch and were able to provide written informed consent. All questionnaires were completed at a single time-point. Demographic data, characteristics of the trauma, and medical data were extracted retrospectively from the Dutch trauma registry and from a general questionnaire. The Abbreviated Injury Scale (AIS) and the ISS were used to determine both the injured body area and the severity of the injuries.

QOL was measured with the Dutch version of the World Health Organization Quality of Life assessment instrument-BREF (WHOQOL-BREF).[25;26] This questionnaire consists of two questions on overall QOL and general health and questions within the four domains of Physical health (7 items), Psychological health (6 items), Social relationships (3 items), and the Environment (8 items). Raw domain scores within those four domains were transformed to a 4-20 score.[25] In each domain, higher scores indicate a higher QOL.

Dutch versions of the Hospital Anxiety and Depression Scale (HADS)[27;28], the Impact of Events Scale (IES)[29;30] and the Cognitive Failure Questionnaire (CFQ)[31] were used to assess psychological complaints. Patients were believed to suffer from psychological complaints if they had an HADS score ≥ 11 on at least one of the two subscales (Depression and Anxiety),[27] an IES score ≥ 35,[32] or a CFQ score ≥ 55.[33]

Functional limitations were assessed using the Dutch adaptation of the Short Musculoskeletal Function Assessment (SMFA) questionnaire.[34] This questionnaire was originally designed to measure functional status and HRQOL. The adapted Dutch version of the SMFA was found to be a valid measure in severely injured patients. A three-factor

structure was found with the factors Upper extremity dysfunction, Lower extremity dysfunction and Emotion.[13] The factors Upper and Lower extremity dysfunction mainly contain questions that ask the patients about their functional status. The questions in the factor Emotion are mainly focused on how much patients are debilitated by their physical limitations. In this study, only the scores of the factors Upper and Lower extremity dysfunction were considered, as the SMFA was used in this study to determine the functional limitations of the patients. For each factor, higher scores represent more physical limitations.

The SMFA scores of the severely injured patients were compared with the baseline scores of a reference group (i.e., 351 patients with a wrist or an ankle fracture who had clearly been instructed to provide their pre-injury scores shortly after their trauma).[35]

Statistical analysis

The scores of the SMFA factors Upper extremity dysfunction and Lower extremity dysfunction were not normally distributed. Therefore, nonparametric independent-sample Mann-Whitney U tests were used to investigate the difference in SMFA scores for several trauma- and patient-related variables and to compare the scores of the SMFA factors for patients with and without psychological complaints. In addition, the scores of the traumatized patients were compared with the baseline SMFA scores of a reference group.[35]

An association between psychological complaints and the QOL had previously been determined in our study population.[18] Because an association between physical complaints and QOL had also been found,[13] multiple linear regression analyses were performed to determine whether that association could partially be explained by the physical limitations of the patients. The missing SMFA scores were completely missing at random concerning age, gender, admission time and type and severity of injury. So, the regression analysis were run on the set of patients with full SMFA data (n=128), to ensure that all models are based on the same set of patients. The possible confounding effect of physical limitations in the association between psychological complaints and the QOL (WHOQOL-BREF score) of the patients was determined by introducing the SMFA scores of the factors Upper and Lower extremity dysfunction in this model with psychopathological complaints and QOL. QOL was the dependent variable in this model. The physical limitations were assumed to be a confounder in a QOL domain if introduction of the variables Upper or Lower extremity dysfunction caused a substantial change (>10%) in the regression coefficient of psychological complaints. In addition, interaction terms were added to determine whether physical limitations were an effect modifier in the association between psychopathological complaints and QOL.

The time between the trauma and the completion of the questionnaires was added into this model to investigate whether there was a difference for the patients whose trauma

had occurred further in the past.
The data were analysed using IBM SPSS statistics 19 software (SPSS Chicago, IL, USA; version 19.0). The significance level was $p<0.05$ for all the tests used.

RESULTS

Patients

Patient characteristics have been described extensively elsewhere.[18;24] In sum, 173 severely injured patients (response rate 61%) returned the questionnaires. The mean time since the injury was 2.8 (SD 0.9) years. Most patients were males (69%), with a mean age of 46 (SD 19) years and a median ISS of 21 (interquartile range 17-27). The most common injury was intracranial injury (61%), and 86% of the patients had received ICU treatment (table 1).

Physical functioning

Almost 3 years after their trauma, severely injured patients reported significantly more physical limitations than a reference group (figure 1).

The SMFA scores for Upper and Lower extremity dysfunction were significantly higher in patients with a higher ISS, in patients with spinal injury and in patients who could not return to work after their injury. Older patients, patients who were unemployed at the time of the injury, those who had physical complaints before the trauma, and those with a low education level ($p<0.001$ for both factors) also reported more physical complaints related to both Upper and Lower extremity dysfunction after the trauma. Patients who were living alone or who had a lower extremity injury denoted only significantly higher scores for the factor Lower extremity dysfunction. Patients for whom the trauma had occurred further in the past also reported significantly lower scores, indicating less complaints, for the factor Lower extremity dysfunction ($p=0.006$ for SMFA Lower extremity dysfunction; $p=0.151$ for SMFA Upper extremity dysfunction in a linear regression model). The results for the binominal variables are shown in table 1. Furthermore, the length of in-hospital stay was also significantly correlated with both Upper extremity dysfunction ($p<0.001$) and Lower extremity dysfunction ($p=0.004$).

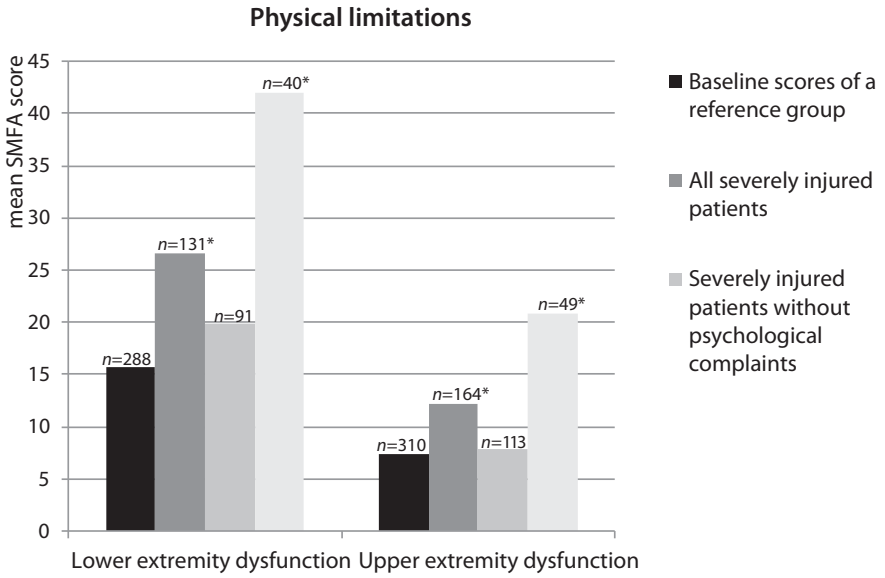

Figure 1. Mean SMFA scores of the factors Upper extremity dysfunction and Lower extremity dysfunction in severely injured patients with and without psychological problems compared with a reference group of the general Dutch population.
* (non-parametric Mann-Whitney test); p< 0.001.

Association between physical functioning and psychological complaints

The patient group with psychological complaints reported significantly higher SMFA scores, indicating more physical limitations, than those of the patient group without psychological complaints (p<0.001). The median values and quartiles are shown in table 2. The mean SMFA scores of patients without psychological complaints did not significantly differ from those of a reference group (Lower extremity dysfunction: p=0.069, Upper extremity dysfunction: p=0.147) (figure 1).

Table 1. Patient characteristics, WHOQOL-BREF scores (N; mean (SD)) for all domains and SMFA scores (N; median (min, max)) for the SMFA factors Upper extremity dysfunction and Lower extremity dysfunction in severely injured patients.

		Patient characteristics n (%)	WHOQOL-BREF					SMFA	
			General n; mean (SD)	Physical n; mean (SD)	Psychological n; mean (SD)	Social n; mean (SD)	Environment n; mean (SD)	Upper extremity dysfunction n; median (min, max)	Lower extremity dysfunction n; median (min, max)
Age	< 55	111 (64)	108; 7,0 (1,9)	107; 14,0 (3,8)	109; 13,8 (3,3)	109; 14,5 (3,6)	109; 14,7 (3,0)	106; 1.1 (0-86,4)	91; 16.7 (0-83,3)
	>= 55	62 (36)	57; 7,4 (1,4)	58; 14,6 (3,1)	58; 14,5 (2,5)	58; 15,4 (2,1)*	58; 15,9 (2,3)*	58; 6.8 (0-100) *	40; 26.7 (0-93,3)*
Gender	Male	120 (69)	114; 7,2 (1,7)	115; 14,4 (3,5)	115; 14,3 (3,0)	115; 14,7 (3,0)	115; 15,1 (2,7)	115; 2.3 (0-100)	90; 17.5 (0-93,3)
	Female	53 (31)	51; 7,0 (1,9)	50; 13,7 (3,6)	52; 13,6 (3,1)	52; 15,1 (3,6)	52; 15,3 (3,0)	49; 4.5 (0-65,9)	41; 21.7 (0-83,3)
Household composition	Alone	40 (23)	39; 6,4 (2,0) *	39; 12,9 (3,7) *	39; 13,1 (3,2) *	39; 13,6 (3,8) *	39; 14,1 (2,9) *	38; 3.4 (0-86,4)	27; 26.7 (1,7-93,3)*
	Together	131 (76)	125; 7,4 (1,6)	125; 14,6 (3,4)	127; 14,4 (2,9)	127; 15,3 (2,8)*	127; 15,5 (2,7)	126; 2.3 (0-100)	104; 15 (0-90)
Employed at the time of injury	Yes	113 (65)	110; 7,2 (1,8)	110; 14,3 (3,5)	112; 14,1 (3,0)	112; 14,8 (3,1)	112; 15,0 (2,9)	108; 2.3 (0-100)	89; 15 (0-90)*
	No	60 (35)	55; 7,0 (1,8)	55; 14,0 (3,6)	55; 14,0 (3,2)	55; 14,9 (3,2)	55; 15,4 (2,7)	56; 4.5 (0-90,9)	42; 26.7 (0-93,3)
Returned to work after injury	Yes	54 (31)	53; 7,9 (1,1)**	53; 16,3 (2,5)**	54; 15,3 (2,3)**	54; 15,5 (2,4)*	54; 16,2 (2,3)**	54; 0 (0-34,1)**	45; 5 (0-61,7)**
	No	55 (32)	53; 6,5 (2,0)	53; 12,6 (3,3)	54; 12,9 (3,2)	54; 14,2 (3,7)	54; 13,9 (2,9)	50; 11.4 (0-100)	42; 33.3 (0-90)
ISS	16-25	97 (56)	90; 7,1 (1,8)	91; 14,2 (3,4)	92; 14,0 (2,9)	92; 14,8 (2,9)	92; 15,1 (2,8)	91; 2.3 (0-100)	74; 13.3 (0-90)
	>= 25	76 (44)	75; 7,2 (1,8)	74; 14,2 (3,7)	75; 14,1 (3,1)	75; 14,9 (3,4)	75; 15,2 (2,9)	73; 4.5 (0-90,9)*	57; 26.7 (0-93,3)*

Table 1. Continued.

			Patient characteristics n (%)	WHOQOL-BREF					SMFA	
				General n; mean (SD)	Physical n; mean (SD)	Psychological n; mean (SD)	Social n; mean (SD)	Environment n; mean (SD)	Upper extremity dysfunction n; median (min, max)	Lower extremity dysfunction n; median (min, max)
AIS region	Head	Yes	131 (76)	123; 7,0 (1,8)	123; 14,1 (3,4)	125; 13,9 (3,0)	125; 14,5 (3,3)*	125; 15,0 (2,8)	123; 2.3 (0-90,9)	101; 20 (0-86,7)
		No	42 (24)	42; 7,4 (1,7)	42; 14,4 (4,0)	42; 14,6 (3,0)	42; 15,8 (2,4)	42; 15,4 (2,7)	41; 4.5 (0-100)	30; 22.5 (0-93,3)
	Face	Yes	46 (27)	44; 6,9 (1,7)	44; 13,7 (3,8)	45; 13,5 (3,0)	45; 14,5 (3,0)	45; 14,8 (2,7)	43; 0 (0-70,5)	37; 20 (0-86,7)
		No	127 (73)	121; 7,2 (1,8)	121; 14,4 (3,4)	122; 14,3 (3,0)	122; 15,0 (3,2)	122; 15,3 (2,9)	121; 2.3 (0-100)	94; 20 (0-93,3)
	Thorax	Yes	71 (41)	69; 7,2 (1,7)	68; 14,5 (3,6)	70; 14,3 (3,0)	70; 15,2 (3,2)	70; 15,7 (2,5)*	67; 4.5 (0-86,4)	51; 16.7 (0-86,7)
		No	102 (59)	96; 7,0 (1,8)	97; 14,0 (3,5)	97; 13,9 (3,0)	97; 14,6 (3,2)	97; 14,7 (3,0)	97; 2.3 (0-100)	80; 20.8 (0-93,3)
	Abdomen	Yes	30 (17)	29; 7,3 (1,8)	30; 14,9 (4,0)	30; 14,6 (3,3)	30; 15,1 (3,7)	30; 15,6 (2,9)	30; 1.1 (0-45,5)	26; 7.5 (0-78,3)
		No	143 (83)	136; 7,1 (1,8)	135; 14,0 (3,4)	137; 13,9 (3,0)	137; 14,8 (3,0)	137; 15,0 (2,8)	134; 2.3 (0-100)	105; 21.7 (0-93,3)
	Spine	Yes	38 (22)	38; 6,9 (1,8)	37; 13,3 (3,6)	38; 13,7 (2,7)	38; 14,9 (2,8)	38; 14,2 (2,5)*	35; 6.8 (0-100)*	26; 33.3 (1,7-93,3)*
		No	135 (78)	127; 7,2 (1,8)	128; 14,4 (3,5)	129; 14,2 (3,1)	129; 14,8 (3,3)	129; 15,4 (2,8)	129; 2.3 (0-77,3)	105; 18.3 (0-86,7)
	Upper extremity	Yes	53 (31)	50; 7,0 (1,8)	48; 13,9 (3,5)	50; 13,7 (3,3)	50; 15,1 (3,3)	50; 14,7 (2,9)	50; 4.5 (0-86,4)	40; 24.2 (0-86,7)
		No	120 (69)	115; 7,2 (1,8)	117; 14,3 (3,6)	117; 14,2 (2,9)	117; 14,8 (3,1)	117; 15,3 (2,8)	114; 2.3 (0-100)	91; 20 (0-93,3)
	Lower extremity	Yes	53 (31)	49; 6,9 (1,8)	48; 14,0 (3,7)	50; 13,9 (3,1)	50; 15,0 (3,3)	50; 15,1 (3,0)	49; 2.3 (0-70,5)	38; 32.5 (0-86,7)*
		No	120 (69)	116; 7,2 (1,8)	117; 14,3 (3,5)	117; 14,1 (3,0)	117; 14,8 (3,1)	117; 15,2 (2,7)	115; 2.3 (0-100)	93; 15 (0-93,3)
Physical disorders before injury	Yes		43 (25)	42; 6,7 (2,0)	42; 12,9 (3,4)*	42; 13,6 (3,2)	42; 14,2 (3,3)	42; 14,4 (2,7)	40; 19.3 (0-90,9)**	28; 55.8 (0-93,3)**
	No		129 (75)	122; 7,2 (1,7)	122; 14,6 (3,5)	124; 14,2 (3,0)	124; 15,1 (3,1)	124; 15,4 (2,8)	124; 0 (0-100)	103; 13.3 (0-76,7)
Mental treatment before injury	Yes		16 (10)	16; 6,1 (2,6)*	16; 12,4 (4,5)*	16; 11,5 (4,0)*	16; 13,7 (4,5)	16; 13,8 (4,1)	14; 3.4 (0-65,9)	12; 37.5 (0-83,3)
	No		156 (90)	149; 7,2 (1,6)	149; 14,4 (3,4)	151; 14,3 (2,8)	151; 15,0 (3,0)	151; 15,3 (2,6)	149; 2.3 (0-100)	119; 20 (0-93,3)
Received ICU treatment	Yes		148 (86)	143; 7,1 (1,8)	143; 14,2 (3,6)	145; 14,0 (3,1)	145; 14,9 (3,1)	145; 15,1 (2,9)	141; 2.3 (0-100)	112; 20.8 (0-93,3)
	No		25 (14)	22; 7,4 (1,7)	22; 14,2 (3,2)	22; 14,2 (2,5)	22; 14,7 (3,5)	22; 15,4 (2,4)	23; 2.3 (0-65,9)	19; 15 (0-61,7)

* $p < 0.05$; ** $p < 0.001$ in nonparametric independent-samples Mann-Whitney U tests for SMFA scores and in independent Student's t-tests for WHOQOL-BREF scores.

Table 2. SMFA scores for both Upper extremity dysfunction and Lower extremity dysfunction were significantly decreased in severely injured patients with psychological complaints compared to patients without psychological complaints. The median values and first and third quartiles are presented.

	Upper extremity dysfunction	Lower extremity dysfunction
With psychological complaints	15.9 (2.3-31.8)*	36.7 (21.7-62.1)*
	n=49	*n*=40
Without psychological complaints	0.0 (0.0-6.8)	10.0 (3.3-30.0)
	n=113	*n*=91

Non-parametric Mann-Whitney test; * p<0.001 compared with patients without psychological complaints.

Association between physical functioning, psychological complaints and QOL

Introducing the factor Lower extremity dysfunction into a model with psychological complaints and QOL caused a substantial change (>10%) in the regression coefficient of the psychological complaints variable for all WHOQOL-BREF domains (table 3). Introducing the factor Upper extremity dysfunction instead of Lower extremity dysfunction changed this regression coefficient as well, but to a lesser extent. Adding the factor Upper extremity dysfunction to the model with the variables Lower extremity dysfunction and Psychological complaints did not alter the regression coefficient for the effect of psychological complaints on QOL (table 3). In all WHOQOL-BREF domains, neither the interaction term between psychological complaints and Upper extremity dysfunction nor the interaction term between psychological complaints and Lower extremity dysfunction was significant. These results did not depend on the time that had elapsed between the trauma and the completion of the questionnaires (figure 2).

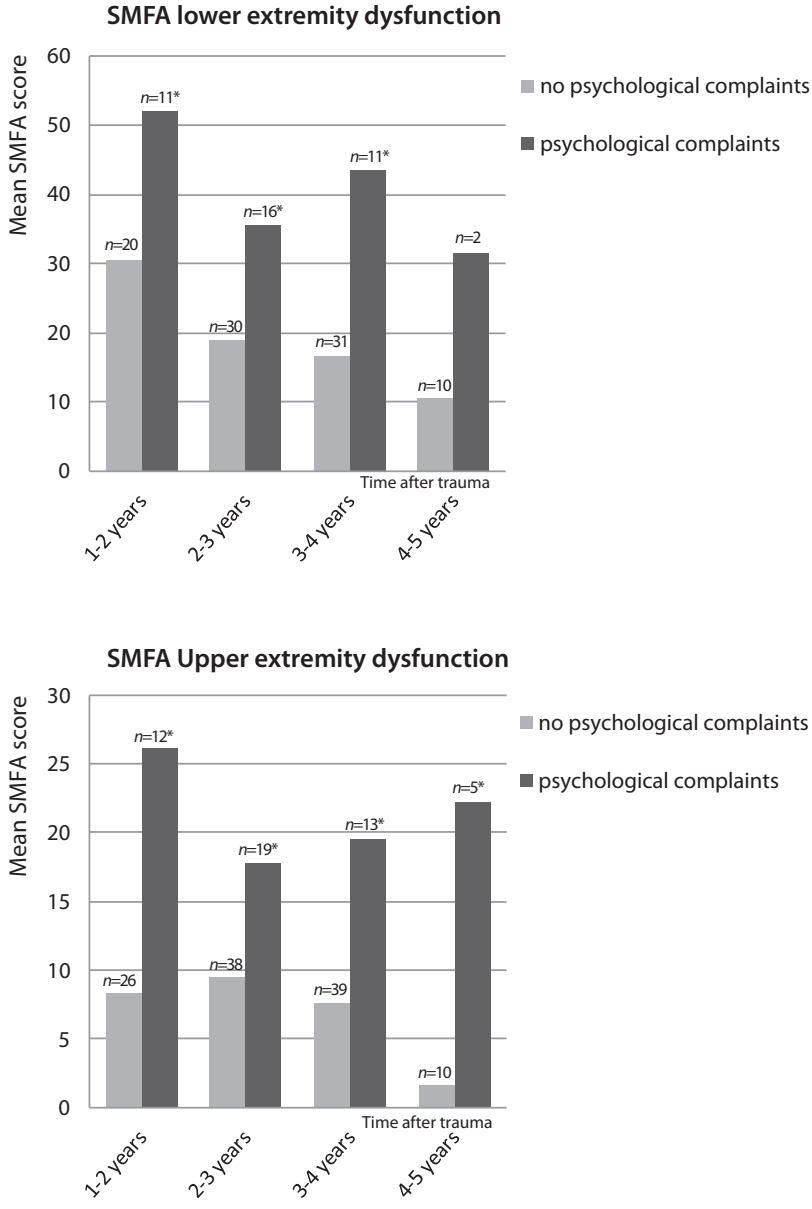

Figure 2. Comparison of mean SMFA scores of the factors Upper extremity dysfunction and Lower extremity dysfunction in severely injured patients with and without psychological problems for four groups of patients with a different time that elapsed between their trauma and the completion of the questionnaires.
* (non-parametric Mann-Whitney test); $p < 0.001$ in the comparison between patients with and without psychological problems.

Table 3. Results from the multiple linear regression analysis of severely injured patients with/without psychological complaints for quality of life, adjusted for physical limitations.

	WHOQOL-BREF				
	General *n*=126	**Physical** *n*=127	**Psychological** *n*=128	**Social** *n*=128	**Environmental** *n*=128
Psychological complaints present	-1.9 (-2.5 to -1.3) p<0.001 R^2=0.234	-4.1 (-5.3 to -2.9) p<0.001 R^2=0.279	-4.1 (-5.0 to -3.1) p<0.001 R^2=0.376	-2.1 (-3.3 to -0.9) p=0.001 R^2=0.091	-3.1 (-4.0 to -2.1) p<0.001 R^2=0.239
Psychological complaints present, adjusting for the following factors					
SMFA Lower extremity dysfunction	-1.3 (-1.9 to -0.7)* p<0.001 R^2=0.333	-2.3 (-3.4 to -1.3)* p<0.001 R^2=0.521	-3.2 (-4.2 to -2.3)* p<0.001 R^2=0.440	-1.4 (-2.7 to -0.2)* p=0.028 R^2=0.132	-2.0 (-3.0 to -1.0)* p<0.001 R^2=0.363
SFMA Upper extremity dysfunction	-1.7 (-2.3 to -1.0)* p<0.001 R^2=0.256	-3.3 (-4.5 to -2.2)* p<0.001 R^2=0.355	-3.8 (-4.8 to -2.8) p<0.001 R^2=0.390	-1.8 (-3.0 to -0.5) P=0.006 R^2=0.109	-2.5 (-3.5 to -1.6)* p<0.001 R^2=0.291
SMFA Upper extremity dysfunction and SMFA Lower extremity dysfunction	-1.3 (-1.9 to -0.7) P<0.001 R^2=0.342	-2.3 (-3.4 to -1.3) P<0.001 R^2=0.530	-3.3 (-4.3 to -2.3) P<0.001 R^2=0.447	-1.4 (-2.7 to -0.2) P=0.028 R^2=0.133	-2.0 (-3.0 to -1.0) P<0.001 R^2=0.364

Beta and 95% confidence intervals, p-values and R^2 values for the unstandardized regression coefficients from a linear regression model are shown.
R^2 (= variance explained by variables)
* Confounding. The variables SMFA Lower extremity dysfunction and SFMA Upper extremity dysfunction were adjusted to a simple linear regression model with psychological complaints and the dependent variable QOL in the different QOL domains. Confounding is based on a 10% change of the regression coefficient (Beta) of psychological complaints in this model. Upper extremity dysfunction and Lower extremity dysfunction were both confounders in this model if they were adjusted. Adjustment of both variables did not change the model that had only been corrected for Lower extremity dysfunction.

DISCUSSION

The first objective of our study was to examine physical function among severely injured patients and its relationship with trauma-related and patient-related factors. In agreement with the results from former studies that described long-lasting physical limitations after a severe injury,[6;12;20] the severely injured patients in this study reported more physical limitations than a reference group. However, patients without psychological complaints did not report more physical complaints than a reference group. The observed increase in physical limitations seemed to be primarily reported by the severely injured patients who were suffering from psychological complaints. Previous studies also reported a relationship between posttraumatic psychological complaints and impaired functional outcome.[20;22;23]

In addition, older patients and patients with a higher ISS, a longer in-hospital stay, physical complaints before the trauma, or an injury of the spine or the lower extremities reported more physical limitations. Similar associations were found in a previous study, except for the association between ISS and physical limitations.[36] This may be due to different inclusion and exclusion criteria because MackKenzie et al. included less severely injured patients and excluded patients with severe brain injury in their study. Holtslag et al. also mentioned age, comorbidity, and spinal cord or extremity injury as predictors of long-term disability after major trauma.[37]

The association between physical limitations and employment or educational level is in agreement with previous studies, in which employment and educational level were important predictors of long-term functional problems after a severe injury.[38;39] Possibly, patients with a low education more often have a job that requests greater physical capacities, resulting in more physical complaints before the trauma. If there are physical sequelae of the injury, this may also cause more difficulties in returning to work or could even result in unemployment.

Although the improvement in physical functionality seems to occur mainly in the first year after the trauma,[40] Soberg et al. also found better physical function in the second year after the trauma compared with the first year.[12] In our study, we found a long-term positive effect of time on Lower extremity dysfunction. In agreement with the results found in a previous study,[41] many patients reported no long-term problems in the function of their upper extremities. Most likely, the process of recovery from an injury to the upper extremities had already been completed when the questionnaires were completed.

In previous studies, brain injury was described as a predictor of disability.[37;39;41] In prior research, trends towards a difference in physical limitations between patients with and without brain injury and in the extent to which patients with and without brain injury seem to be debilitated by their limitations were found.[13] In addition, patients with both

a brain injury and a moderate rating of disability reported a lower life satisfaction rating than patients with either a severe or mild disability rating.[42] In that context, it would have been relevant to perform subgroup analyses of patients with and without brain injury with respect to physical limitations and QOL. However, the patient numbers were insufficient to produce reliable and significant results. Therefore, a larger study would be advisable to facilitate subgroup analysis.

The second objective of this study was to determine whether an association between psychological complaints and QOL could be explained by the physical limitations of the patients. The association between psychological complaints and QOL was not different between patients with and without physical limitations, as no effect modification was found. Further, the variance of the decrease in QOL of patients with psychological complaints could partially be explained by their physical limitations, as physical limitations of both the upper and lower extremities were confounders in the association between psychological complaints and QOL. The confounding effect was larger for Lower extremity dysfunction than for Upper extremity dysfunction. This is probably due to a complete recovery of injuries to the upper extremities, given the large ceiling effect for the factor Upper extremity dysfunction. Stalp et al. also found more functional limitations for patients with injuries to the lower extremities two years after multiple blunt injuries.[9] Patients with an injury to the upper extremities needed a shorter rehabilitation phase to get similar results in functionality than patients with injuries of comparable severity to the lower extremities. In addition, pain may be a relevant component in explaining the different effect of functional limitations in the upper and lower extremities. More than half of the patients reported that they still suffered from severe pain that persisted two years after their trauma.[15] Patients with lower limb injuries often have a larger quantity and more constant pain than patients with upper limb injuries. This would be reflected in more restricted function of the lower extremities, which results in restricted movement. This makes patients with lower limb injuries more dependent on others. Therefore, functional limitations of the lower extremities will have a larger impact on the social aspects of life than comparable complaints of the upper extremities. The above factors may result in a later and more difficult acceptance of sequelae for patients with injuries to the lower extremities.

It is still unclear how the association between physical limitations, psychological complaints and QOL operates and which comes first. Physical limitations might cause decreased QOL, but physical limitations may also cause psychological complaints and influence QOL indirectly. Moreover, patients with psychological complaints might suffer more from similar functional limitations or experience more physical limitations

than patients without psychological complaints even though their objective physical abilities are similar. This should be further investigated.
Physical limitations might be more important for (HR)QOL directly after the trauma because patients and doctors are mainly working to achieve good physical recovery at that moment. Psychological factors may become more important later for some patients, when the patients realize that they will have to live with the sequelae of the trauma such as permanent impairment. Indeed, previous studies found that physical wellbeing was further decreased after the trauma than mental wellbeing[5;8] but that the overall decrease in HRQOL remained and primarily had a psychological basis.[5] Future studies should follow patients over time to determine how physical limitations and psychological complaints develop over time while investigating how these factors influence each other.

Multidisciplinary revalidation programmes are now mainly accessible for trauma survivors with a poor physical recovery. It should be explored whether not only patients with a low physical recovery but also patients for whom low QOL or psychological problems are expected could benefit from revalidation programmes. Several parameters that were associated with physical limitations are also associated with QOL, such as inability to return to work, physical complaints before the trauma, or low educational level. As described above, educational level and physical limitations may be related to return to work. Patients who cannot regain their previous job or become unemployed may experience lower QOL, but it is also possible that patients with decreased QOL need more time to return to work. Age and ISS were not related to QOL in our study population,[24] although older patients and more severely injured patients reported more physical limitations. Older patients may have accepted their physical limitations easier because they might be used to the expectation of physical limitations due to ageing. Very severely injured patients may accept their limitations easier, as they are mainly happy to still be alive. In addition, the process of acceptance may start earlier if it is immediately evident that previous activity levels will not be regained.
The physical limitations themselves seem less important for QOL than the extent to which patients are bothered by them.[13] Therefore, it might be worthwhile to help patients to accept their limitations and to try to decrease the extent to which they are bothered by their experienced limitations. This might be possible by focusing on the patients' capacities instead of their limitations during the revalidation process. This kind of assistance may particularly be helpful for patients with characteristics such as psychological complaints, comorbidities, low education and lack of employment.

Some limitations of this study should be mentioned. Selection bias cannot be excluded, as the response rate was 61%. However, the groups of respondents and non-

respondents were comparable, except for a slight overrepresentation of women in the respondent group. Although QOL and physical limitations were not found to be gender-dependent, women reported psychological complaints more often than men in our study population. In addition, recall bias may have influenced the results because the condition of the patients before their trauma can only be determined retrospectively in trauma care studies.

Furthermore, the SMFA Upper extremity dysfunction value could not be determined for all patients because some patients did not complete all questions of the questionnaire. We assume that some of those patients accidentally did not receive the last page of the questionnaire because 12 patients did not return this page. Therefore, the responses to the last ten questions of the SMFA were missing for those patients. We assume that the missing values did not influence the outcomes of our study, as the missing responses were randomly spread among the study population. None of the questions of the last page were incorporated in the factor Upper extremity dysfunction, and only two of these questions were incorporated in the factor Lower extremity dysfunction.

Because of the cross-sectional design of the study, it was impossible to investigate the exact interaction between physical limitations, psychological complaints and QOL or to determine which one preceded the others. In addition, the number of patients was insufficient to perform subgroup analyses according to the type of conditions (e.g., brain injury or extremity injury). Therefore, it would be advisable to perform larger prospective follow-up studies in the future.

CONCLUSION

Approximately 3 years after a severe injury, physical limitations were mainly reported by patients with psychological complaints. Physical limitations seem to be important in the association between psychological complaints and QOL. In the longer term, functional limitations of the lower extremities seem to be particularly relevant. However, it is unclear how the interaction between physical limitations, psychological complaints and QOL operates and which one precedes the others. For treatment purposes, the development of this association should be further investigated in larger, longitudinal follow-up studies in the future. Furthermore, several patient- and injury-related characteristics that were associated with QOL were also associated with physical limitations (e.g., physical complaints before the injury, education level and employment status). Such parameters may be used to select patients for whom a multidisciplinary rehabilitation programme would be useful.

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CHAPTER 6

Long term outcome and patients' personality in severely injured trauma patients

C.C.H.M. van Delft-Schreurs
M.A.C. de Jongh
M.H.J. Verhofstad
J. de Vries

submitted.

ABSTRACT

Introduction

In recent years more studies focus on the outcome parameter (Health Related) Quality of Life ((HR)QOL) after a severe injury. Psychological complaints are known to be associated with (HR)QOL. However, little is known about long-term QOL. Studies in other fields, have shown that apart from disease patients' personality may be associated with (long-term) QOL.

The aim of this study was to evaluate QOL, psychological complaints and physical limitations about ten years after a severe injury and to compare this with the patients' situation 7 years earlier. Furthermore, the association between long-term QOL and the patients' personality was examined.

Methods

The 156 patients who participated in a study to investigate QOL, psychological problems and physical limitations seven years ago, were reassessed to determine their current situation using the same questionnaires as seven years earlier. In addition, patients' personality was assessed.

Results

The response rate was 58%. Except for the social component, no significant differences in patients' QOL, psychological complaints and physical limitations were found, in comparison with seven years earlier. The social domain scores decreased. Personality was significantly associated with all QOL domains. Psychological complaints were not an important confounder in the interaction between personality and long-term QOL.

Conclusions

The QOL, psychological and physical situation of severely injured patients ten years after their injury is comparable to their situation three years after their injury. Personality was an important factor, strongly associated with long-term QOL. Therapy focused at extending coping strategies may be helpful for patients at risk for a low QOL, since no further spontaneous recovery was found.

INTRODUCTION

With the growing number of trauma survivors,[1] the focus in trauma research is shifting from mortality to non-fatal outcome parameters, like (health related) quality of life ((HR)QOL). Previous studies showed that severely injured patients are suffering from long-lasting physical disabilities[2-5] and that the (HR)QOL of severely injured patients is decreased compared with the general population.[6-12] A strong association was found between the physical limitations of the patients and their (HR)QOL.[13-15] Furthermore, psychological problems of trauma survivors were shown to be an important, possibly underestimated factor for their decreased (HR)QOL.[16-20]
In a previous cross-sectional study among severely injured patients, strong correlations between the psychological complaints and QOL, and between physical limitations and QOL were found 1.3 to 4.4 years after their trauma.[13;18] The time between the trauma and the completion of the questionnaires did not significantly influence the QOL nor the psychological complaints within that patient group.[18;21] Study results of most previous long-term studies are based on outcome parameters up to one or two years after trauma. Little is known about (very) long-term outcome. The few previous studies about long-term health status (HS) or HRQOL after a severe injury often focused on traumatic brain injury.[22-24] The existing studies reported that values are still below general population norms or below scores of a matched control group six to ten years after the injury.[23;25;26] Even less is known about the developments over time, because of a lack of long-term prospective studies. One study reports that HS and HRQOL decreased ten years after mild traumatic brain injury compared with the first year after injury.[24]
In the current study we compared QOL, physical limitations and psychological complaints ten years after the patients' injury with their situation seven years earlier.

Several studies examined which factors are associated with QOL after an injury to identify the patients that are at risk for a low QOL. Although the duration of hospitalization and duration of ICU treatment were found to be correlated with decreased physical QOL scores,[21, 24] injury or trauma related factors hardly seem to correlate with long-term QOL.[11;21;23;27-29] Spinal cord injury, lower extremity injury and brain injury were mentioned as possible predictors of functioning or QOL.[24;30;31]
Some other factors that are found to be associated with QOL after a severe injury, such as psychological complaints, experiencing physical constraints and loss of work,[12;14;32] will only be detectable a while after the injury and may fluctuate over time.
So, it is a challenge to find stable factors that can be used at an early stage to select patients who, in the long run, are at risk for a low QOL. Personality is considered to be stable over time and associations between personality traits and QOL were reported

in oncological, cardiological and orthopaedic studies.[33-36] The personality characteristic Trait anxiety was a predictor for QOL three months after an ankle fracture.[37] Furthermore, until one year after an ankle fracture or a distal radius fracture higher scores on the personality characteristics Trait anxiety and Neuroticism, and lower scores on the personality characteristic Extraversion were found in patients with lower QOL.[38] The relationship between personality and QOL and the relationship between personality and the extent to which patients suffer from physical limitations is not yet examined in severely injured patients.

The aim of this study was to evaluate the QOL, psychological complaints, and physical limitations in severely injured patients about ten years after their injury occurred and to compare these scores with the patients' situation 7 years earlier. Furthermore, we examined the association between patients' personality and their long-term QOL and physical limitations.

METHODS

Patients

The 156 patients who were still alive and participated in a study to investigate QOL, psychological problems, and physical limitations seven years ago[13;18;21], were reassessed to determine their current situation. Their current QOL, psychological and functional outcome were measured similarly as 7 years before. Besides, the patients' personality was determined.

Study procedures

Eligible patients received a letter asking them to complete some questionnaires about their long-term situation after a severe injury in a similar way as seven years earlier. They were asked to return the completed questionnaires together with a consent form for participation in an attached reply envelope.
The METC provided a statement that it concerns non-WMO research.

QOL, functional limitations and psychological complaints

Methods and questionnaires to determine QOL, functional outcome, and psychological complaints have been described extensively in the publications of the previous study.[13;18;21] Briefly, the QOL was measured with the Dutch version of the World Health Organization Quality of Life assessment instrument-BREF (WHOQOL-BREF).[39;40] Higher scores indicate a better QOL.

Functional limitations were investigated with the three SMFA factors Upper extremity dysfunction, Lower extremity dysfunction and Emotion of the SMFA, which were found previously for severely injured patients.[13] Higher scores indicate more limitations.
Psychological complaints were, as previously, measured by several general questionnaires. The Hospital Anxiety and Depression Scale (HADS)[41] was used to screen for anxiety and depressive disorders, the Dutch version of the Impact of Events Scale (IES; validated translation known as "Schokverwerkingslijst"[42]) as an indicator for PTSD and the Cognitive Failure Questionnaire (CFQ) to assess subjective cognitive complaints. Patients with a HADS subscale value ≥ 11, an IES score ≥ 35 or an CFQ score ≥ 55 were considered to have psychological problems.[43-45]

Personality
The Neuroticism scale and Extraversion scale of the *NEO-Five Factor Inventory (NEO-FFI)* were used to measure the personality characteristics Neuroticism and Extraversion, which both consist of 12 items.[46-48] The items were rated on a five-point Likert-scales (1 = strongly disagree; 5 = strongly agree). The psychometric characteristics of the NEO-FFI appeared to be sufficient.[46]
The short version of the Trait anxiety scale, derived from the *State-Trait Anxiety Inventory (STAI),* was used to determine the tendency to experience anxiety across situations.[49;50] Items were scored on a four-point Likert-scales (1 = almost never; 4 = almost always). Higher Trait anxiety scores indicated more overall anxiety. The short version is a reliable and valid measure.[51]

Patient, injury and admission variables
Patient characteristics (e.g. age, sex), injury characteristics (e.g. The Abbreviated Injury Scale (AIS-90, update 98)[52] and ISS[53;54]) and admission characteristics (e.g. length of hospital stay, admission to IC-unit), have been extracted from the Dutch trauma register and questionnaires in the previous study. Relevant patient characteristics that may have been changed (e.g. household composition, work) were asked again in this study.
Besides, the patients were asked whether they found that they had changed since the injury event.

Statistical analysis
All analyses were conducted using SPSS version 24.0 (Statistical Package for Social Sciences, Chicago, IL, USA). Frequencies and descriptive statistics were calculated to provide an overview of the characteristics of the study population. Student's t-tests were used to compare continuous variables of the study population that participated with the non-participants, including the deceased patients. Chi-square tests were performed

for nominal variables. Paired student's t-tests were conducted to compare QOL and SMFA scores between the two time points. Patients with and without psychological complaints were compared between the two time points with the McNemar test for paired samples. For outcome parameters that did not follow a normal distribution (like the SMFA scores), the paired nonparametric independent-sample Wilcoxon signed rank was used. Linear regressions were run to investigate the association between the patients' personality and QOL in combination with psychological complaints. The significance level was 0.05 for all used tests.

RESULTS

The response rate was 58%. The characteristics of the group of patients that participated in the current study (n=90) did not differ from the characteristics of the group that only participated in the previous study, except for the social QOL domain (p=0.009) and the environmental QOL domain (p=0.017). For both domains the scores were higher for the patients who participated in the current study. Besides, the number of patients that only participated in the previous study and had a job before the injury was slightly lower than the number of patients with a job before the injury who participated in the current study (p=0.047). A flowchart is presented in figure 1 and patient characteristics are presented in table 1.

The QOL scores and physical limitations 10 years after a severe injury were comparable to the situation about 3 years after their injury. Only the social QOL was decreased in comparison with 7 years earlier. Mean difference QOL and SMFA scores are presented in table 2.

The group of patients with psychological complaints did not change significantly. Most patients (54) did not have psychological complaints in current study as well as in the previous study or reported psychological complaints at both moments (17). Seven patients who had psychological problems, did not report those problems anymore. On the other hand, nine patients without psychological problems in the previous study, reported psychological problems ten years after their injury. Patients who experienced psychological complaints did not mention other factors for these complaints apart from the injury or injury event.

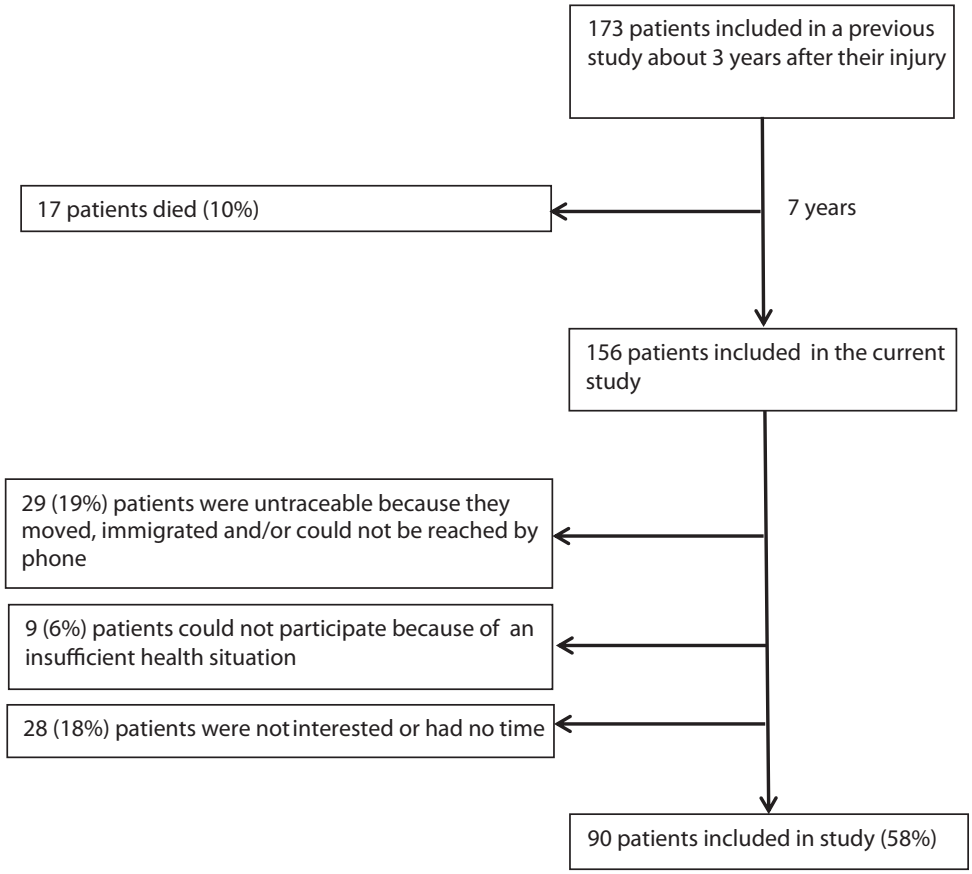

Figure 1. Flowchart of the selection of eligible patients. The 156 patients participants of a previous study (about 7 years before the current study) in which QOL, psychological problems, and physical limitations of severely injured patient were investigated, were reassessed to determine their situation (about 10 years (8.5-11.5) after their injury).

Table 1. Comparison of patient characteristics of severely injured patients, determined in a study about 7 years before the current study, from patients who were only included, in that previous study and from patients who were included in both the previous and the current study (about 10 years after their injury). P-values (*p < 0.05) of Student's t-tests, Chi-square tests and Non parametric Mann-Whitney U Tests were respectively shown for continuous variables and nominal variables and the SMFA scores.

Characteristic determined 7 years before current study	Only included in previous study n (%)	Included in long term study n (%)	p-value
Participation	83 (48)	90 (52)	
head	65 (78)	66 (73)	0.445
face	24 (29)	22 (24)	0.506
abdomen	13 (16)	17 (19)	0.576
thorax	36 (43)	35 (39)	0.549
spine	22 (27)	16 (18)	0.166
Upper extremities	24 (29)	29 (32)	0.637
Lower extremities	30 (36)	23 (26)	0.131
Employed before injury	48 (58)	65 (72)	0.047*
Returned to work	20 (out of 47)	34 (out of 62)	0.204
HADS Depression	14 (17.3)	7 (8)	0.066
HADS Anxiousness	12 (14.8)	12 (13.5)	0.803
CFQ	14 (18.4)	9 (10.1)	0.125
SVL	9 (12.7)	10 (10.2)	0.621
Psychological complaints	28 (35.9)	24 (27.7)	0.214
Gender (female)	32 (25.3)	21 (35.5)	0.144
	Mean (SD)	Mean (SD)	
Age (years)	47.5 (21.6)	46.3 (17.0)	0.684
ISS	22.5 (6.8)	24.2 (8.2)	0.140
WHOQOL physical	13.8 (3.3)	14.6 (3.7)	0.139
WHOQOL psychological	13.7 (3.1)	14.4 (3.0)	0.741
WHOQOL social	14.2 (3.2)	15.4 (3.0)	0.009*
WHOQOL environment	14.6 (2.8)	15.6 (2.7)	0.017*
WHOQOL general	6.5 (1.9)	7.4 (1.7)	0.065
	Median (IQR)	Median (IQR)	
SMFA lower extremity dysfunction	20.8 (5.0-48.8)	20.0 (5.0-40.8)	0.663
SMFA upper extremity dysfunction	2.3 (0.0-18.2)	2.3 (0.0-15.9)	0.601
SMFA emotion	32.5 (15.0-52.5)	30.0 (15.0-50.0)	0.418
In hospital stay (days)	14.0 (7.0-28.0)	17.5 (9.0-40.0)	0.227
IC stay (days)	14.0 (20.7)	16.4 (20.2)	0.476

Table 2. Mean difference in QOL (WHOQOL-BREF scores) and physical limitations (SMFA scores) between current values (about 10 years after the injury) and the scores of the similar questionnaires 7 years earlier in the same study population.

	n	QOL 10 yrs after injury Mean (SD)	Difference 10yrs vs 3 yrs Mean (SD)	Student's t-test p-value	Non- parametric Wilcoxon signed ranking test p-value
WHOQOL-BREF general	86	7.4 (1.8)	0.06 (1.50)	0.720	
WHOQOL-BREF physical	87	14.5 (3.5)	-0.03 (2.65)	0.920	
WHOQOL-BREF psychological	88	14.4 (2.9)	-0.02 (2.34)	0.923	
WHOQOL-BREF social	89	14.4 (3.4)	-1.08 (2.67)	<0.001*	
WHOQOL-BREF environmental	89	15.5 (2.6)	-0.16 (2.10)	0.471	
SMFA Lower extremity dysfunction (Median IQR)	75	16.7 (6.7-46.7)	1.78 (12.72)	0.230	0.482
SMFA Upper extremity dysfunction (Median IQR)	88	0.0 (0.0-10.2)	-0.15 (12.53)	0.908	0.171
SMFA Emotion (Median IQR)	75	30.0 (14.4-48.8)	-0.73 (13.01)	0.627	0.492

* $p < 0.05$ in a paired student's t-tests.

All three measured personality characteristics were associated with QOL in all domains. Extraversion had a positive association with QOL in all domains. Higher scores on Neuroticism and Trait anxiety were negatively associated with QOL. Trait anxiety resulted in the highest explained variance in all domains (R^2 between 0.414 (social domain) and 0.679 (psychological domain)). Extraversion provided the lowest explained variance (R^2 between 0.182 (domain environment) and 0.430 (psychological domain)). See table 3.

Concerning the physical limitations, personality resulted in the highest explained variance for the domain Emotion (R^2=0.620 for Neuroticism). Regarding the domains Upper extremity dysfunction and Lower extremity dysfunction, Neuroticism had the highest explained variance (R^2=0.172 for Lower extremity dysfunction) and Trait anxiety (R^2=0.107) for Upper extremity dysfunction. Extraversion provided the lowest explained variance for physical limitations and had a negative association with physical limitations. Neuroticism and Trait anxiety were positively associated with physical limitations. See table 4.

Table 3. Results from the multiple linear regression analysis of the NEO-FII scores of the personality characteristics Neuroticism, Extraversion or Trait anxiety of severely injured patients and their quality of life (QOL) about 10 years after their injury, adjusted for the psychological complaints. Beta and 95% confidence intervals, p-values (* $p < 0.05$) and R^2 values for the unstandardized regression coefficients from a linear regression model are shown.
R^2 (= variance explained by variables)
Confounding. The variables psychological complaints were adjusted to simple linear regression models with personality characteristics Neuroticism, Extraversion or Trait anxiety and the dependent variable QOL in the different QOL domains. Confounding was based on a 10% change of the regression coefficient (Beta) of the personality characteristics in this model.

	WHOQOL-BREF				
	General	**Physical**	**Psychological**	**Social**	**Environmental**
Trait anxiety	-0.19 (-0.23 to -0.16)	-0.34 (-0.42 to -0.27)	-0.35 (-0.40 to -0.30)	-0.32 (-0.40 to -0.24)	-0.27 (-0.33 to -0.21)
n=86	p<0.001*	p<0.001*	p<0.001*	p<0.001*	p<0.001*
	R^2=0.596	R^2=0.478	R^2=0.679	R^2=0.414	R^2=0.487
Extraversion	0.13 (0.10 to 0.17)	0.20 (0.12 to 0.28)	0.24 (0.18 to 0.30)	0.24 (0.16 to 0.31)	0.14 (0.07 to 0.21)
n=83	p<0.001*	p<0.001*	p<0.001*	p<0.001*	p<0.001*
	R^2=0.383	R^2=0.222	R^2=0.430	R^2=0.304	R^2=0.182
Neuroticism	-0.12 (-0.15 to -0.09)	-0.25 (-0.30 to -0.19)	-0.25 (-0.29 to -0.21)	-0.21 (-0.27 to -0.15)	-0.17 (-0.22 to -0.13)
n=86	p<0.001*	p<0.001*	p<0.001*	p<0.001*	p<0.001*
	R^2=0.440	R^2=0.478	R^2=0.676	R^2=0.353	R^2=0.392
Trait anxiety adjusted for psychological complaints	-0.20 (-0.25 to -0.15)	-0.31 (-0.42 to -0.20)	-0.28 (-0.35 to -0.21)	-0.28 (-0.39 to -0.16)	-0.24 (-0.32 to -0.15)
	p<0.001*	p<0.001*	p<0.001*	p<0.001*	p<0.001*
n=86	R^2=0.596	R^2=0.482	R^2=0.706	R^2=0.421	R^2=0.493
Extraversion adjusted for psychological complaints	0.11 (0.07 to 0.15)	0.13 (0.04 to 0.22)	0.16 (0.10 to 0.22)	0.17 (0.09 to 0.25)	0.08 (0.01 to 0.15)
	p<0.001*	p=0.003*	p<0.001*	p<0.001*	p=0.020*
n=83	R^2=0.446	R^2=0.326	R^2=0.621	R^2=0.400	R^2=0.310
Neuroticism adjusted for psychological complaints	-0.10 (-0.14 to -0.06)	-0.21 (-0.28 to -0.14)	-0.19 (-0.24 to -0.15)	-0.16 (-0.23 to -0.08)	-0.13 (-0.19 to -0.07)
	p<0.001*	p<0.001*	p<0.001*	p<0.001*	p<0.001*
n=86	R^2=0.462	R^2=0.495	R^2=0.733	R^2=0.390	R^2=0.429

Table 4. Results from the multiple linear regression analysis of the NEO-FII scores of the personality characteristics Neuroticism, Extraversion or Trait anxiety of severely injured patients and their physical limitations (SMFA-scores) about 10 years after their injury, adjusted for the psychological complaints.
Beta and 95% confidence intervals, p-values (* $p < 0.05$) and R^2 values for the unstandardized regression coefficients from a linear regression model are shown. R^2 (= variance explained by variables)
Confounding. The variables psychological complaints were adjusted to simple linear regression models with personality characteristics Neuroticism, Extraversion or Trait anxiety and the dependent variable physical limitations (SMFA) for the factors Upper extremity limitations, Lower extremity limitations and Emotion. Confounding was based on a 10% change of the regression coefficient (Beta) of the personality characteristics in this model.

	SMFA		
	Lower extremity limitations	**Upper extremity limitations**	**SMFA Emotion**
Trait anxiety *n*=86	1.34 (0.56 to 2.12) p=0.001* R^2=0.125	0.90 (0.34 to 1.46) p=0.002* R^2=0.107	2.49 (1.98 to 3.00) p=0.000* R^2=0.553
Extraversion *n*=83	-0.99 (-1.67 to -0.30) p=0.005* R^2=0.095	-0.57 (-1.08 to -0.05) p=0.031 R^2=0.056	-1.32 (-1.88 to -0.76) p=0.000* R^2=0.226
Neuroticism *n*=86	1.09 (0.56 to 1.61) p=0.000* R^2=0.172	0.58 (0.17 to 0.99) p=0.006* R^2=0.088	1.80 (1.48 to 2.11) p=0.000* R^2=0.620
Trait anxiety adjusted for psychological complaints *n*=86	0.83 (-0.25 to 1.92) p=0.131 R^2=0.144	0.48 (-0.30 to 1.27) p=0.225 R^2=0.130	1.88 (1.19 to 2.57) p<0.001* R^2=0.587
Extraversion adjusted for psychological complaints *n*=83	-0.65 (-1.40 to 0.11) p=0.091 R^2=0.140	-0.27 (-0.83 to 0.29) p=0.337 R^2=0.117	-0.61 (-1.14 to -0.08) p=0.024 R^2=0.466
Neuroticism adjusted for psychological complaints *n*=86	0.85 (0.18 to 1.52) p=0.013 R^2=0.186	0.27 (-0.24 to 0.78) p=0.289 R^2=0.127	1.43 (1.04 to 1.82) p<0.001* R^2=0.659

The variable Psychological complaints was a small confounder in both the interaction between personality and complaints and QOL and in the interaction between personality and physical limitations.
Two third of the patients (59) indicated that they had changed since their injury (see table 5). Most of them became more emotional or tired (16), suffered from mental decline or concentration loss or became more forgetful (13). Eight patients became more positive/calm and 11 found themselves more assertive/direct/confidential or open.

Table 5. Results of the answers that patients provided on the question: "Did you change since the injury event?"

Did you change since the injury event?	n (%)	Specification change	n
No change	29 (32.2)		
Changed	59 (65.6)	physical complaints	11
		less confidence/interested/enthusiasm	5
		more emotional/tired	16
		mental decline/concentration loss/forgetful	13
		more positive life setting/calm	8
		more assertive/direct/confidence/open	5
		changed, not positive nor negative	3
		unknown	8
Unknown	2 (2.2)		

DISCUSSION

The first aim of this study was to investigate long-term QOL, psychological complaints and physical limitations after a severe injury, and to compare this with the patients' situation 7 years earlier.

To our knowledge, this is the first study that reveals that the physical and psychological situation and QOL stabilize in the first three years after a severe injury. Our results showed that the QOL, the physical situation, and psychological complaints of severely injured patients about ten year after the injury remained more or less similar to the situation seven years earlier, except for the social QOL. So, QOL scores of patients were still below general population scores about ten years after a severe injury. This is in agreement with results of the existing long-term studies among patients with a severe injury.[22;23;25;26] A previous study reported that HRQOL decreased 10 years after brain injury compared with the first year after the injury.[24] This, in combination with the results of the current study, suggests that QOL stabilizes somewhere between the first and third year after a severe injury. It would be advisable to follow patients in longitudinal study to determine the moment of this stabilisation more specifically. Such information can be used to find the most appropriate moment for eventual interventions.

The social QOL declined the second 5-year period after the injury. This is also in agreement with results from a previous study.[55] The mean social domain QOL score of seven years ago was significantly higher in the group of patients that participated in the current study than in the group of patients that only participated in the study seven

years ago. So, the real decrease in the social QOL is probably greater than measured, because of this selection bias. The decrease in social QOL was expected because the patient's relatives, friends and acquaintances partially lose interest in patients' health problems if the injury event is longer ago. The decrease in social QOL is in agreement with results found in studies among patients with cancer.[56;57]
Thirty percent of our study population had psychological complaints. A previous study found a depression rate of 31% ten years after moderate-to-severe traumatic brain injury (TBI).[23]
Nine persons developed psychological complaints during the last seven years. This also happens in the general population, although to a lesser extent. The patients did not indicate other factors for their experienced psychological problems than the injury or accident. Therefore, the injury or injury event seems to play a crucial role in developing psychological problems in these patients years after the injury took place.

The second goal of this study was to investigated the effect of the patients' personality on QOL and functional limitations after a severe injury.
In line with results of some oncological, cardiological and orthopedic studies,[33-36] all three personality factors were associated with QOL in all domains. Concerning Trait anxiety, this result concurs with a previous study that found that Trait anxiety was a significant predictor for all QOL domains in patients with an ankle fracture[37] and results of a recent study suggest that the psychological aspects of QOL were associated with an emotional coping style after spinal cord injury.[58]
Extraversion was positively associated with QOL in all domains. Neuroticism and a stronger Trait anxiety had a negatively association with QOL. This was expected, because it is known that patients with higher Neuroticism scores and a stronger Trait anxiety more often suffer from mental illness. It is also in agreement with results found in patients until one year after an ankle fracture or a distal radius fracture.[38] Trait anxiety was even the most important predictor of social QOL in patients with ankle fracture,[37] the only QOL domain in which the QOL still decreased in the second 5-year period after the injury event.

Although two thirds of the patients found that they had changed since the injury event, patients' personality traits are assumed to be stable and, therefore, may be useful to predict whether a patient is at risk for low QOL after the injury. So, it seems important that health care professionals become more aware that personality characteristics may influence a patient's QOL and may be a useful tool to determine patients who are at risk for long-term complaints or a low long-term QOL. Those patients may then benefit from patient education and possibly psychological counselling in changing coping strategies concerning handling effects of the injury at an early stage.

Interventions like offering therapy in which a more adaptive coping strategy is provided, seems promising, because recovery after whiplash injury was shown to be influenced by pain coping strategies,[59] and training with relaxation strategies after knee arthroplasty resulted in improvements in function compared to usual care.[60] Therefore, it may be advantageous for severely injured patients to know about the relationship between personality characteristics, experienced physical limitations and QOL. They could be informed about the influence of the extent to which they express themselves, and about the influence of their thoughts and feelings of the experiences after their injury.
Besides, it might also be efficient and cost-effective to take the patients' personality into account, when choosing for a specific therapy for a patient who is recovering from an injury. After all, a quicker recovery or acceptance of the remaining sequelae ensures lower healthcare costs.
So, it seems advisable to inform patients about the relationship between personality characteristics and QOL, to provide them insight in their personality and provide coping strategies to deal with these personality characteristics.

CONCLUSION

The QOL, psychological and physical situation of severely injured patients ten years after their injury is comparable to their situation three years after their injury. Personality is an important factor for long-term QOL and it may be advantageous to provide the patients insight in their personality and provide coping strategies to deal with these personality characteristics.

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CHAPTER 7

General discussion

GENERAL DISCUSSION

The aim of the studies in this thesis was to gain more insight into the quality of life (QOL), psychological complaints and physical limitations of severely injured patients (ISS> 15) mid- and long-term after their rehabilitation phase and to investigate factors that may affect the mid-term outcome parameters. This information can be used to identify patients at risk for a worse outcome in an early stage and to offer them additional personalized care. One-hundred-and-seventy-three patients were included 15-53 months after their injury. They completed questionnaires to investigate their QOL, psychological complaints, and physical limitations. Ten years after their injury, 90 patients completed the same questionnaires again to compare their situation with seven years earlier.

About three years after the injury QOL was decreased in all domains except for the social domain, in patients with psychological complaints. The QOL scores and physical limitations had not changed seven years later. Only the social QOL score had decreased in comparison to seven years before.
Co-morbidity before the accident, unemployment, a low education level and living alone were associated with a risk for low QOL. QOL was also associated with both psychological complaints and physical limitations. Thirty percent of the study population had psychological complaints. The reduced QOL experienced by patients with psychological complaints could partly be explained by the remaining physical limitations of the lower extremities. Moreover, personality seems to be important for the experienced QOL. Patients who score higher on introversion, neuroticism, and trait anxiety reported a worse QOL and more physical limitations than patients with low scores on those personality factor scales. Personality was an important confounder in the relationship between psychological complaints and QOL.

METHODOLOGICAL CONSIDERATIONS

Population

All severely injured trauma patients were included in the studies, to provide a complete insight into the role of the type or severity of the injury. This is one of the strengths of this thesis. Some previous studies included only patients with very specific injuries.[1-3] In that case, less numbers are needed to determine associations between physical limitations, psychological complaints or QOL and injuries of a specific body region. As a drawback of this uniformity, it is more complicated to compare subgroups.

An Injury Severity Score (ISS) > 15, which is most commonly used to discriminate between severely and less severely injured patients, was also used to select severely injured patients in the studies of this thesis. However, in agreement with most Health Status (HS) and Health Related Quality of Life (HRQOL) studies,[4-8] we found no relationship between ISS and QOL. This independence may be due to the fact that mortality risk is the underlying outcome parameter for the ISS.[9] QOL or persisting functional limitations are not disconcerted in the ISS. Once a patient has survived and the threat to life disappeared, parameters that are not involved in survival chances seem to be more important for a good recovery. Patients who lose their upper limb or a foot and have no other injuries have an ISS of nine. Thus, from the ISS point of view they don't have a severe injury, as it is not life threatening. However, it is conceivable that those patients who initially had high survival chances may have severe functional limitations and psychological complaints . At the end, those patients may be more severely injured in terms of long-term burden, because of persisting severe functional limitations and psychological complaints and may also experience a decreased long-term (HR)QOL.
So, the ISS was probably not the most appropriate parameter to select patients with a severe injury in terms of long-term QOL, physical limitations and psychological complaints. Although the ISS is recorded for all admitted trauma patients by default in the Netherlands, this is most often calculated after discharge. The ISS was available in the registry for our study population, but it is less appropriate to identify severely injured patients directly after or even already before discharge.

Most other determinants that are known to be associated with low (HR)QOL after an injury, like comorbidity[10], psychological complaints, return to work,[11-13] a low socio-economic status[14], or a low education level,[15] had not been established in the study population before the study started. Those parameters are usually not available in the medical records by default. Length of hospital stay or ICU days may have been used as an additional variable to select the study population where the most mid- and long-term

problems are expected. However, to our knowledge there is no cut-off value available. The results of the last study in this thesis showed that personality characteristics, may provide a good starting point to determine which patients with a severe injury are at risk for mid- and long-term low QOL.

The study population consisted of patients who were invited to participate in the cross-sectional study one to three years after a severe injury. Most previous studies who investigated mid-term burden after an injury included patients one or two years after their injury, at which point many patients may just have finished their rehabilitation phase. In this light these studies concern short-term outcome. So, one of the added values of this thesis is that the studies measured mid- and long-term outcome.
However, the relatively long term that passed between the patients' discharge from hospital and the start of the study also had some disadvantages. It may have caused recall bias concerning questions about the patients pre-injury treatment. As time elapses, other confounding factors (e.g., a severe medical disease or condition) may occur and blur the association between the original accident and the outcome parameters measured in this thesis.

Furthermore, some patients felt too bad to participate and some others could not be traced. Both factors will induce a certain degree of selection bias. If so, the QOL as presented in this thesis is probably too positive. A relative of the patients who felt too bad to participate could have been asked, but we decided to refrain from this solution, because relatives are not always good proxies for patients' QOL because they respond from their own view of the patient.[16]

Following the results of the studies in this thesis, a prospective follow-up study (BIOS), has been started in which patients data is collected by self-reported questionnaires at 6 time points between the first week and 24 months after injury. [17] Patients were also asked for their pre-injury scores in the first week. However, it seemed a challenge to include all eligible patients, because they had to be trace and contact within a week. Caregivers had to be aware and prepared to inform patients. Furthermore, just after the accident, patients were not always interested in a research study or capable to participate.

Instruments/questionnaires

A strength of the studies in this thesis is that patients completed questionnaires about QOL, physical- and psychological complaints at the same moment. This provided possibilities to investigate the associations between those variables.
Furthermore, patients were asked about their pre-injury physical health and mental treatment during the first measurement moment. These data are always lacking in trauma care studies, as a correct baseline value from the same individuals is not available. Severe injury is a sudden event with often a long recovery time. No one knows upfront if he will get injured. So, the patients' pre-injury situation can only be asked retrospectively. Therefore, a general population reference group was used for comparison of the QOL scores. SMFA values of the general population were not available. The pre-injury scores of another study population were used as a reference group, as this was assumed to be the second best option. However, the opinion about the pre-injury physical situation may have been distorted. The Patients of the reference group who were asked for their pre-injury functioning could have experience a huge decrease in physical possibilities because of their injury. Therefore, they may have thought that they had more physical capabilities before their injury than they actually had. So, information bias cannot be excluded. Furthermore, scores from the general population may not completely reflect reality, if the trauma population is not an exact reflection of the general population.[18;19] If more characteristics about the trauma population become available, reference value from the general Dutch population may be adjusted for deviating determinants. A reference group that better reflects the whole trauma population may be composed then.

There is a large variation in the use of (HR)QOL instruments.[20] In contrast with most previous studies, who measured HRQOL or HS, we wanted to investigate QOL. Therefore, the WHOQOL-BREF[21] was chosen. This questionnaire measures QOL as defined by the World Health Organization Quality of Life (WHOQOL) Group[11;22] and also includes patients' satisfaction with functioning and whether the patients' evaluation of functioning is in line with their expectations. Ideally, only questionnaires that already have been validated in a comparable study population are used. The WHOQOL-BREF had not yet been validated in a severely injured trauma population, but it has validated psychometric properties in other patient groups in several countries, including the Netherlands.[23-27] Moreover, a recent study showed that the Dutch version of the WHOQOL-BREF can be used accurately to assess QOL in a heterogeneous group of hospitalized trauma patients.[28]

The physical limitations were measured with the Dutch adapted version of the SMFA. This Dutch version had not been validated before this study started. This generic SMFA questionnaire was nevertheless preferred over multiple injury-specific questionnaires, because body region specific questionnaires are less useful in examining physical limitations in severely injured patients, with multiple affected body regions. Several body region specific questionnaires should otherwise have been completed. Moreover, the SMFA was designed with a Function- and a Bother index to measure HS and QOL of patients with a broad range of musculoskeletal injuries and disorders.[29] Because the translation and validation of the questionnaire in other languages showed good results,[30;31] it was expected that the Dutch adapted version would be valid as well. This was confirmed in this thesis. However, the factor analysis in our Dutch version provided three factors with fewer questions in the population of severely injured patients instead of the original function and bother index. This makes it difficult to compare the SMFA scores with other non-Dutch patient populations. The Dutch adapted version was also validated in patients with fractures of the upper or lower extremities.[32] This also resulted in another set of appropriate questions. However, the creation of several Dutch versions of the SMFA is not preferred. To maintain the strength of having one generic questionnaire for different disorders and to promote comparability, it would be advisable to investigate the overlap between the questionnaires and to find out whether it is possible to generate one Dutch SMFA for several injuries.

IMPLICATIONS AND RECOMMENDATIONS

Assessment of physical and psychosocial problems

Some patients in the study found it too burdensome to complete all questionnaires and, therefore, a subgroup refrained from participation. To improve the response rate, a questionnaire should be short. The outcome scores of all used questionnaires in our study are strongly associated with each other. Besides, the studies of this thesis showed that physical limitations, psychological complaints and a decreased QOL often have the similar important risk factors. This may offer possibilities to develop a short screening questionnaire for risk factors, that cannot be retrieved from the medical records like personality, psychological problems, education level and the social economic status. It is of course important to use the most appropriate questionnaire for a specific research question, because each questionnaire has its own focus. We used several questionnaires, because our studies aimed to investigate several determinants that could be related with QOL. However, for use in clinical practice like the identification of patients with additional health care needs at an early stage, it raises the question

whether it is necessary to use all these questionnaires. At least short(er) questionnaires would be advisable. In addition, agreement and consensus on preferred questionnaires makes it easier to compare different studies and to compose a representative reference value for injured patients. An innovative possibility for measuring (HR)QOL are computer-adaptive tests (CATs). Those tests are based on the item response theory (IRT). CATs select the most informative items from an item bank for each individual patient based on previous answers and the underlying latent trait.[33] Therefore, patients receive tailor-made follow-up questions and only have to answer the most informative and discriminating questions for his or her situation. So, less questions are needed, which makes it less burdensome in comparison with the regularly used questionnaires. However, until now CATs are mainly available for generic questionnaires and it will offer less opportunities to compare patients or patient groups with each other, because all patients receive a different set of questions.

Furthermore, it would be helpful if screening questionnaires with risk factors are incorporated in the regular health care systems and if the information can directly be used to identify patients who are at risk for low non-fatal outcome and need additional or specialized care. This makes it more efficient to deliver the most appropriate customized care. In that way registration systems will get more added value and will not only be useful to measure, report or justify delivered care. They will become a tool to achieve valid predictions and support personalized health care. Such screening questionnaires can also be used to follow patients over time and to start communication with them about topics that seem to need additional attention. A short screening questionnaire that recently has been developed, the psychosocial screening instrument for trauma patients (PSIT) (at this moment unpublished), will be incorporated in a new aftercare outpatient clinic.

If patients go to the outpatient clinic for a control visit they may be asked to complete some patient reported outcome measures (PROMs) in their Electronic Medical Record (EMR) to provide the doctor with some information about their experienced physical limitations, psychosocial situation and personality. However, not all patients are seen in the outpatient clinic after discharge, especially if they went to a rehabilitation centre. It would be an option to invite patients to complete some questions in a patient portal of the EMR. This should than be combined with the existing information. This requires that patients have the opportunity and possibilities to complete the questions. Chain registry can also help to follow the patients. Although this will be a challenge, because this requires agreement on uniform outcome measures and commitment to collect and share this information. Furthermore, chain partners usually use different software in their organisations. Those systems should use a similar language to connect them. Of

course, the strict privacy guidelines also have to be followed. However, it is essential that patients get the most appropriate care at the right moment. This may prevent unnecessary problems in patients and at the end save time and reduce cost.

Furthermore, it will only make sense to ask patients to provide additional information if the patient can benefit from the requested information and if it will be followed up with appropriate treatment. A case-manager may be helpful to coordinate this and to coordinate transmural processes for patients who may need additional care after discharge or after an visit to the outpatient clinic. This requires additional resources but may also reduce health care costs as described earlier.

In the Netherlands it may be an option to integrate non-fatal outcome measurements in the national trauma registry to get more insight in non-fatal burden of the trauma population. This will be a challenge, because registry is time consuming and patients have to be contacted. Besides, the new European privacy guidelines must be followed.

Future research

Follow-up study

Although there are strong associations between QOL, physical limitations and psychological complaints, the interactions between those parameters are still unclear. Possibly, patients who first suffer from physical complaints, develop psychological complaints. Continuing pain, accepting physical limitations or adjustment of expectations may be important when no further progression in physical recovery is made. But psychological complaints may also influence the perception of physical limitations. One study reported that the physical situation of major trauma patients improved in the second part of the year after the injury. Mental health decreased the first 18 months, but improved 18-24 months after the injury.[34] It is also unknown when patients become aware of their decreased QOL. In short, a prospective long-term follow-up study is advisable to investigate changes across time and the causality between physical and mental problems. Revealing this for a patient is relevant since psychological problems may be prevented.

Few follow-up studies have been performed.[34-36] None of them exceeded two years follow up and they did not investigate the interaction between physical and psychological complaints. The results of **chapter 6** in this thesis showed that about ten years after the injury, neither the average QOL scores nor the average SMFA scores had changed compared to seven years earlier. The groups of patients with and without psychological complaints also did not change significantly. This suggests that for most

patients the situation stabilizes somewhere in the first years after the injury and will hardly change any more without interventions. To find the most appropriate moment for interventions, it is advisable to follow patients in a longitudinal prospective study to get more information about this moment of stabilization. However, personalized care is probably necessary, since this may differ for individual patients.

Subgroup analysis and risk profiles

Fortunately, some patients have no or minimal long-term sequelae of their severe injury. To prevent over-treatment and to identify patients who may benefit from additional care, risk profiles should be established. Measuring and investigating factors that are associated with non-fatal outcome parameters facilitates the development of a prediction model and provides the opportunity to compose risk profiles for developing low QOL or psychological problems after severe injury in survivors. Risk profiles should be generated to select patients who are at risk for remaining functional or psychological complaints or low (HR)QOL. These profiles should be based on patient characteristics, medical measures and on psychosocial information from PROMs.

Subgroup analyses are needed to establish which injuries result in a high risk for worse long-term outcome. In this thesis subgroups were often too small for subgroup analysis and it was difficult to assign limitations to an injury of one specific body region because the patients often had injuries in several body regions. Injury of the lower extremities and the spine seemed to result in the most long lasting physical limitations. Multicenter studies are probably necessary for this purpose, because one hospital often does not have enough patients of a similar isolated injury in a relative short timeframe. Subgroup analysis for patients with brain injury also seems to be advisable. We found a tendency that brain injury may result in more emotional problems (higher SMFA-emo) and a decreased QOL compared with other severe injuries. Because the severity of the injury (ISS) does not seem to be the most important factor for QOL, less severely injured patients may also suffer from long-term problems. So, Subgroup analysis of a less severely injured trauma population is recommended.

Furthermore, stratification for age should be considered in future research. Because of the ageing of the population, the number of frail severely injured elderly patients increases. Those patients have other injuries and trauma mechanisms than younger patients.[37] Besides, for older patients long-term illness seems to be more relevant than the injured body region.[36] Besides, the impact of treatment (e.g. surgery) should be taken in consideration. The huge impact of surgery on frail elderly may be a reason to discuss whether usual care, which usually means surgery, is also the best solution for such fragile patient, if quality of life is explicitly included in the considerations. Shared decision making,

a way of working in which the doctor and the patient decide together which options for treatment best meets the patient's desires, can be important in these situations.

We found that inability to return to work was an important determinant for a decreased QOL for younger patients. Several other determinants were found to be associated with QOL after injury like gender, length of hospital stay, ICU days, injury severity, comorbidity, posttraumatic stress symptoms, post injury depression and serious injury of the extremities.[10-13]
Return to work, an important factor for QOL, can only be measured longer time after the injury, when the decreased QOL already may exists. Psychological complaints, another important factor that is associated with QOL, can change across time. These parameters, therefore, offer fewer possibilities to identify patients who are at risk for a low QOL at an early stage. Other parameters are more stable across time and can be measured at an early stage, like a low socio-economic status[14], a low education level,[15] discrepancies of the CT scan, headache at the emergency room,[38] or headache 3 months after brain injury,[39] but cannot easily be changed.
The patient's personality can be a useful part of a risk profile to identify patients who are at risk for a low QOL at an early stage, because it is stable over time, relatively easy to determine, and patients can be offered psychological counselling to learn the accept changes in their lives and learn adaptive coping strategies.

Interventions
The results provide a basis for various intervention studies. For instance, it should be investigated whether more introvert injured patients with high Neuroticism or Trait anxiety scores, can benefit from learning to use other coping styles, when their preferred style does not help them in dealing with their remaining problems. Another intervention study could focus on the role of systematically providing information to patients about what they can expect with regard to physical and mental recovery. Recognizing problems and awareness about dominant coping styles could be useful. This should of course only be implemented for patients who need this additional help.

Patients at risk for low QOL should be identified using a short, easy to complete screening tool containing the risk factors. The most appropriate measurement moment should be determined, but it seems important to assess potential risk factors as soon as possible. Once communication with a patient is possible, he/she should be contacted personally to generate a confidential relationship. The patient may optimally benefit if he/she feels free to address problems at a stage when problems have not yet fully emerged. Somatic caregivers should be aware of the importance of early communication to become

intrinsically motivated. However, the patient may not yet be ready to think about living with the consequences of the accident, if he or she is still working on the physical recovery. So, the patient has to be prepared and ready for this. A study examining the effect and time of implementing a screening tool is needed. Moreover, screening is only useful, if follow-up with appropriate treatment is possible.

An app could be helpful for positive thinking exercises or to follow-up patients with an increased risk of psychological problems. Furthermore, appropriate moments for determining a patient's personality, starting the conversation with the patient about this issue and eventually offering therapy should also be investigated. The usefulness of such an app can be examined.

If selected groups of patients may benefit from specific treatment strategies to decrease their complaints and improve their possibilities to return to or participate in society and increase their QOL, this may also reduce the medical and societal costs of severely injury. This cost-effectiveness topic is also relevant to examine.

In short, subgroup analysis should be performed to provide risk profiles for identifying patients who are at risk for low long-term outcome. The risk factors should be included simultaneously to investigate associations and confounding. The risk factors should be used to develop a short questionnaire. Besides, it should be investigated how those questionnaire could be used most efficiently to decrease the registration burden. A long-term follow-up study should be performed to investigate changes across time and to identify the best moment for eventual interventions. Furthermore, the result of different possible interventions like extending coping strategies, shared decision making or apps should be investigated. The cost-effectiveness of such interventions should be investigated as well.

Clinical implications

It is beyond dispute that patients and medical doctors desire an optimal recovery. Currently, optimal recovery is often mainly based on the patient's physical condition. QOL deserves more attention as this may be a more relevant indicator for recovery from the patient's perspective and from a broader perspective. This would also be in line with the growing interest in value based health care.[40] The studies of this thesis showed that psychological factors influences mid- and long-term QOL. Therefore, these factors should receive more attention in a structural way. This should be implemented in care.

In addition, it is important to find out whether the physical complaints decrease a patient's QOL or that psychological factors influence the patient's experiences of physical limitations and QOL. It is important to discuss these different options with the patient and to decide whether it is most important to have objectively fewer physical complaints or to be less bothered by possible remaining complaints. If patients unjustly keep hope for full physical recovery, patients may be better off learning how to accept and cope with residual symptoms. Patients then may experience a better QOL, despite existing limitations or complaints. Perhaps the focus should sometimes shift from a possible (re)operation that may give little physical progression, to learning how to deal with remaining limitations. This means that information about what patients may expect from medical interventions should be discussed with the patient. Shared decision making is important in this respect.

The patient's personality and corresponding problem-solving skills seem to be important. Therefore, some patients could benefit from problem-solving skills interventions. To provide customized care, patients should be identified based on investigated risk profiles, to select the patients who may benefit from such interventions and to prevent additional health care for patients who don't need this. Communication is important to know what the patients desires and expectations are and to inform the patients whether this is realistic. This can be realized by implementing multidisciplinary trauma care teams and rehabilitation programs in which psychological care is involved as regular care for severely injured trauma patients. This should not be limited to patients who are very severely injured in terms of an anatomical injury scale like the ISS. Positive effects of such approach may also be expected for patients with a less life threatening injury, which are expected to result in long-term physical limitations or physical complaints, like patient who lost a foot or have injuries which may result scars in the face.

Severely injured patients who still have residual symptoms after two years, should be considered as patients with a chronic disease, as those symptoms often become permanent. A visit to the outpatient clinic every (half) year is usually standard care for patients with a chronic disease. However, some severely injured patients go home or go to a rehabilitation center and go home afterwards, but do not know who they should contact if they have any questions. Factors that influence QOL of patients with a chronic disease, such as pain, fatigue, and a meaningful life may also be important for severely injured patients. Developing a relying screening questionnaire as mentioned above, to identify patients who can benefit from psychotherapy, should be completed to identify patients who should be seen again at the outpatient clinic.

GENERAL CONCLUSION

Mid-term and long-term QOL is decreased in severely injured patients. The severity of the injury is not related to the level of QOL. Patients' personality, pre-existing psychological complaints, comorbidity, and return to work seem important determinants for QOL years after the injury occurred. There is an association between QOL, physical limitations and psychological complaints. In the long run, psychological complaints seem more important than physical limitations. More than 3 years after the injury, the situation seems to have become more or less stable. The patients' personality can be a starting point to find and help people who can benefit from other coping styles than their preferred one.

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CHAPTER 8

Summary

SUMMARY

In the Netherlands, annually about 80,000 trauma patients are admitted to a hospital because of their injury. This is known, because data from these patients are recorded in the Dutch trauma registry. In this registration, an injury severity score (ISS), which ranges from 1-75, is determined for all admitted trauma patients. Patients with a score above 15 are considered severely injured patients. Approximately 5 to 6% of the trauma patients in the Netherlands are severely injured. Little is known about the mid- and long-term consequences of a severe injury.
The studies in this thesis were conducted to gain more insight into the mid- and long-term physical limitations, psychological complaints and quality of life (QOL) of severely injured patients (ISS> 15) and factors that may affect these outcome parameters.
One-hundred-and-seventy-three patients completed questionnaires to investigate their mid-term QOL, psychological complaints, and physical limitations (15-53 months after their injury). Furthermore, associations between the measured outcome parameters and patient and injury characteristics were investigated. Seven years later, 90 patients completed the same questionnaires again to investigate long-term outcome and to compare their situation with seven years earlier. In addition, some aspects of their personality were determined to investigate associations between long-term burden and the patients' personality. **Chapter 1** contains a general introduction for the studies in this thesis.

In **chapter 2** subgroup analyses were performed to investigate which relationships exist between specific injuries and QOL. Moreover, associations between accident- and patient-related factors and the QOL of severely injured patients were examined. Severely injured patients appeared to have a lower mid-term QOL than a reference group of the Dutch population, except for the social domain. QOL was decreased in all domains for patients who had brain injury in combination with other injuries. Patients with brain injury, without other severe injuries, only reported a reduced QOL in the physical domain. Co-morbidity before the accident, a longer in hospital or ICU stay, unemployment and living alone seemed a risk for a decreased QOL. The injury severity and the type of injury were not associated with QOL.

In **chapter 3** the incidence of psychological complaints and the relationship of these complaints with the QOL and accident- and patient-related factors was investigated. To measure psychological complaints, several questionnaires were used. The Dutch version of the Hospital Anxiety and Depression Scale (HADS), the Impact of Events Scale (IES) and the Cognitive Failure Questionnaire (CFQ) were used to measure respectively symptoms

of anxiety, depression, post-traumatic stress disease, or subjective cognitive symptoms. Thirty percent of the study population had psychological complaints 15-53 months after their accident. In comparison with a reference group of the Dutch population, QOL was only decreased for patients with psychological complaints. No association was found between existing psychological complaints and the injury severity or the type of injury. Patients who were treated for psychological complaints or used medication before their injury, reported more psychological complaints than patients without treatment or medication before the injury. Patients who were employed at the time of the study, reported fewer psychological complaints than patients without a job.

In **chapter 4** the Dutch adapted version of the Short Musculoskeletal Function Assessment (SMFA) was validated for severely injured patients. The SMFA was used to measure the physical limitations, because it is a frequently used generic questionnaire for measuring physical limitations, which is translated and validated in different languages. More specific questionnaires, which focus on one injured body region are less useful for severely injured patients, because those patients have different injuries. The original SMFA consists of two parts. The first part focuses on functional limitations. The second part focuses on QOL by asking how much the patients are bothered by their limitations. A three factors structure, which consisted of the factors Complaints to the upper extremities (arms), Complaints to the lower extremities (legs) and Emotion, was found in the Dutch adapted version. The psychometric properties were good and the questionnaire provided information about both HS and QOL.

Chapter 5 describes which factors were associated with physical residual symptoms. In addition, the association between the psychological complaints and remaining physical limitations was investigated. Physical complaints before the accident, lower education level, unemployment, or living alone, a more severe injury, injuries of the spine or lower extremities (legs) and a higher age seemed risk factors for more mid-term physical limitations. Particularly, patients with psychological complaints still experienced physical limitations after their rehabilitation phase. The reduced QOL experienced by patients with psychological complaints could partly be explained by the remaining physical limitations of the lower extremities.

In **chapter 6** the QOL, physical limitations and psychological complaints were determined 10 years after the accident. In addition, the association between these long-term outcome and personality traits of the patients was investigated. Neuroticism, Extraversion and State anxiety were measured. The long-term burden of the patients (approximately 10 years after the injury) was almost comparable to their situation 7 years

earlier. Only the social QOL was lower than 7 years before. So, without interventions, no changes are expected more than three years after the injury.
Patients who scored higher on introversion, neuroticism and state anxiety experienced a lower QOL and more physical limitations. Neuroticism and state anxiety seemed most important. The association between personality traits and QOL can partially be explained by the psychological complaints of the patients. Personality may be a good determinant to identify patients who are at risk for a low long-term QOL. Those patients might benefit from learning to use other coping styles.

The general discussion in **chapter 7** describes some implications and recommendations. Additional research is necessary to provide more information on risk profiles. Larger groups of patients are needed to provide risk profiles that can be used to identify patients who are at risk for a low long-term outcome. These risk factors should be used to develop a short screening questionnaire and it should be investigated how such questionnaires can be incorporated in regular health care systems. Results from screening questionnaires should result in appropriate follow-up treatment. Multidisciplinary trauma care teams and rehabilitation programs, in which psychological care is common care for severely injured trauma patients, is advisable and a case manager may be helpful to coordinate personalized care. Results of interventions that may help to decrease the complaints and improve the possibilities to return to and/or participate in society, like offering extending coping strategies, should be investigated. A long-term prospective follow-up study should be performed to identify the best moment for interventions, when needed.

CHAPTER 9

Dutch summary
Nederlandse samenvatting

SAMENVATTING

In Nederland worden elk jaar zo'n 80.000 patiënten opgenomen in een ziekenhuis vanwege letsel dat ze bij een ongeval oplopen. Gegevens van deze patiënten, ook wel traumapatiënten genoemd, worden vastgelegd in de Nederlandse traumaregistratie. In deze registratie wordt een totale ernstscore (Injury severity score (ISS)) toegekend aan de combinatie van de letsels van deze patienten. Deze ISS varieert tussen de 1 en 75 en een patiënt wordt als ernstig gewond beschouwd als de ISS hoger is dan 15. Uit de traumaregistratie blijkt dat in Nederland jaarlijks 5 à 6% van de patiënten ernstig gewond is. Veel van deze patiënten houden gevolgen over aan hun ongeval. Er is weinig bekend over deze gevolgen op middellange en lange termijn. De studies in dit proefschrift zijn uitgevoerd om meer inzicht te krijgen in de lichamelijke beperkingen, psychische klachten en kwaliteit van leven (KvL) van ernstig gewonde patiënten op de (middel) lange termijn en factoren die van invloed kunnen zijn op deze uitkomstparameters. Om de KvL, psychische klachten en fysieke beperkingen op de middellange termijn te onderzoeken vulden 173 ernstig gewonde ongevalpatiënten, 15-53 maanden nadat ze hun letsel opliepen, vragenlijsten in. Van deze patiënten zijn de associaties tussen de gemeten uitkomstparameters en patiënt- en letselkenmerken onderzocht. Zeven jaar later vulden 90 patiënten dezelfde vragenlijsten opnieuw in, om te bepalen hoe de uitkomsten van deze patiënten circa 10 jaar na ongeval waren. Daarnaast zijn sommige aspecten van hun persoonlijkheid bepaald om associaties te onderzoeken tussen de langdurige gevolgen en de persoonlijkheid van de patiënten. **Hoofdstuk 1** bevat een algemene inleiding op de studies in dit proefschrift.

In **hoofdstuk 2** zijn subgroepanalyses uitgevoerd om te onderzoeken welke relaties er bestaan tussen specifieke letsels en de KvL. Daarnaast is onderzocht welke ongeval- en patiëntgerelateerde factoren de KvL van ernstig gewonde patiënten beïnvloeden. De KvL is gemeten met de vragenlijst WHOQOL-BREF, een vragenlijst die de KvL meet in de domeinen algemeen, fysiek, psychisch, sociaal en omgeving. Ernstig gewonde patiënten bleken op de middellange termijn een lagere KvL te hebben dan een referentiegroep uit de Nederlandse bevolking, behalve in het sociale domein. Bij de groep patiënten die hersenletsel en daarbij nog ander letsel hadden, was de KvL in alle domeinen verlaagd. Patiënten die alleen hersenletsel hadden, rapporteerden alleen een verlaagde KvL in het fysieke domein. Comorbiditeit vóór het ongeval, een langere verblijfsduur in een ziekenhuis of op de intensive care, werkloosheid en alleen wonen lijken een risico te vormen voor een lagere KvL. De letselernst en het type letsel leken niet van invloed op de KvL.

In **hoofdstuk 3** is de incidentie van psychische klachten en de relatie tussen deze klachten, de KvL, en ongeval- en patiëntenkenmerken onderzocht. Om psychische klachten te meten, zijn er verschillende vragenlijsten gebruikt. De Nederlandse versie van de Hospital Anxiety and Depression Scale (HADS), de Impact of Events Scale (IES) en de Cognitive Failure Questionnaire (CFQ) zijn gebruikt om respectievelijk symptomen van angst, depressie, PTSS of subjectieve cognitieve klachten te meten. Dertig procent van de studiepopulatie had 15-53 maanden na hun ongeval psychische klachten. In vergelijking met een referentiegroep uit de Nederlandse bevolking, bleek de KvL alleen verlaagd te zijn bij patiënten met psychische klachten. Er werd geen relatie gevonden tussen de aanwezigheid van psychische klachten en de letselernst of het type letsel. Patiënten met een betaalde baan vóór het ongeval of op het moment van het onderzoek, hadden minder psychische klachten dan patiënten zonder baan. Patiënten die voor het ongeval medicatie gebruikten of waren behandeld voor psychische klachten, rapporteerden meer psychische klachten ten tijde van het onderzoek, dan patiënten zonder behandeling of medicatie vóór het letsel.

In **hoofdstuk 4** is een Nederlandse aangepaste versie van de Short Musculoskeletal Function Assessment (SMFA) gevalideerd bij ernstig gewonde patiënten. Voor het meten van de fysieke beperkingen is de SMFA gebruikt, omdat dit een veelvuldig gebruikte generieke vragenlijst is voor het meten van fysieke beperkingen, die in verschillende talen vertaald en gevalideerd is. Meer specifieke vragenlijsten zijn niet goed bruikbaar bij ernstig gewonde patiënten, omdat binnen deze groep veel verschillende letsels voorkomen en de patiënten vaak meerdere letsels hebben. De oorspronkelijke SMFA bestaat uit twee delen. Het eerste deel concentreert zich op het meten van functionele beperkingen. In het tweede deel wordt de KvL gemeten door te vragen naar de last die mensen ervaren door hun beperkingen. De uitgevoerde factoranalyse resulteerde in de aangepaste Nederlandse versie in een structuur met drie factoren: klachten aan de bovenste ledematen (armen), klachten aan de onderste ledematen (benen) en emotie. De psychometrische eigenschappen waren goed en de vragenlijst geeft informatie over zowel de gezondheidstoestand van de patiënten als over hun KvL.

In **hoofdstuk 5** is beschreven welke factoren geassocieerd zijn met de fysieke klachten van de patienten. Daarnaast is onderzocht of deze fysieke beperkingen een deel van de associatie tussen psychische klachten en KvL zouden kunnen verklaren.
Lichamelijke klachten vóór het ongeval, een lager opleidingsniveau, werkloosheid, alleen wonen, ernstiger letsel, verwondingen aan de wervelkolom of onderste ledematen of een hogere leeftijd, leken risicofactoren voor meer lichamelijke beperkingen op de middellange termijn. Met name patiënten met psychische klachten bleken nog fysieke

beperkingen te ervaren na afronding van hun revalidatiefase. De verlaagde KvL die de patiënten met psychische klachten ervaren, kan gedeeltelijk verklaard worden door fysieke beperkingen van met name de onderste ledematen.

In **hoofdstuk 6** zijn de KvL, fysieke beperkingen en psychische klachten 10 jaar na het ongeval weergegeven. Daarnaast is de associatie tussen deze langetermijnuitkomsten en een aantal persoonlijkheidskenmerken van de patiënten onderzocht. Daarvoor zijn neuroticisme (de tendens om frequent een intens negatieve toestand te ervaren), extraversie (het neigen naar sociale, assertieve en positieve affectie) en toestandsangst (tijdelijke, momentane, subjectieve, bewust ervaren gevoelens van spanning) gemeten.
De situatie van de patiënten bleek 10 jaar na het ongeval niet veel te verschillen van hun situatie 7 jaar eerder. Alleen de sociale KvL was lager dan 7 jaar ervoor. Als er geen interventies plaatsvinden, lijkt er daarom niet veel aanleiding om meer dan drie jaar na het ongeval nog veel veranderingen te verwachten.
Voor wat betreft de persoonlijkheidskenmerken, rapporteerden patiënten die hoger scoorden op de kenmerken introversie, neuroticisme en toestandsangst een lagere KvL en meer fysieke beperkingen. Neuroticisme en toestandsangst leken daarbij het meest relevant. De psychische klachten die mensen hebben, verklaren een deel van de associatie tussen persoonlijkheidskenmerken en KvL. Persoonlijkheid kan een goede voorspeller zijn om in een vroeg stadium te bepalen welke patiënten op de lange termijn een verhoogd risico lopen op een lage KvL. Deze patiënten kunnen baat hebben bij het leren toepassen van andere coping-stijlen.

De algemene discussie in **hoofdstuk 7** beschrijft enkele implicaties en aanbevelingen naar aanleiding van de in voorgaande hoofdstukken beschreven resultaten en conclusies. Subgroepanalyses worden aanbevolen om risicoprofielen vast te stellen, waarmee patiënten die een risico lopen op slechtere langetermijnuitkomsten onderscheiden en geselecteerd kunnen worden. De risicofactoren kunnen bijvoorbeeld gebruikt worden om een korte screeningvragenlijst te ontwikkelen. Daarnaast wordt aanbevolen te onderzoeken hoe het invullen van dergelijke vragenlijsten kan worden opgenomen in reguliere zorgstelsels, zodat patiënten een passende vervolgbehandeling krijgen. Het implementeren van psychische zorg in multidisciplinaire traumazorgteams en revalidatieprogramma's wordt aanbevolen bij zwaargewonde traumapatiënten. Daarnaast zou een casemanager nuttig kunnen zijn om zorg op maat te coördineren. Interventies die klachten zouden kunnen verminderen en zouden kunnen helpen bij een bevredigende terugkeer in de maatschappij, zoals het aanbieden van andere coping-strategieën, moeten onderzocht worden. Een prospectieve langetermijnstudie wordt aanbevolen om het beste moment voor eventuele interventies te bepalen.

CHAPTER 10

Acknowledgements / Dankwoord

Curriculum vitae

List of publications

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Ook zonder de traumaregistratie was dit onderzoek niet mogelijk geweest. Bij de juiste registratie en inclusie zijn veel medewerkers betrokken. Zonder hun inzet en medewerking, was het niet mogelijk geweest de juiste patiënten voor dit onderzoek te selecteren en de benodigde gegevens te achterhalen. Met name wil ik de registratiemedewerkers Barbera, Marie, Anne-Marie en Miranda, die in het ETZ alle registraties hebben gecontroleerd en waar nodig aangevuld, danken voor hun bijdrage. Het is onmogelijk iedereen die aan de traumaregistratie heeft meegewerkt, persoonlijk te noemen. Bij deze wil ik alle artsen, met name traumachirurgen en SEH-artsen, verpleegkundigen en backofficemedewerkers die hier hun steentje aan hebben bijgedragen, bedanken. Daarnaast wil ik de medewerkers van de afdeling opname bedanken voor hun hulp om ervoor te zorgen dat er geen overleden patiënten werden aangeschreven en ook verhuisde patiënten benaderd konden worden.

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CURRICULUM VITAE

Katinka van Delft-Schreurs was born on September 24th, 1974 in Valkenswaard, the Netherlands. After completing secondary school at 'Hertog-Jan College' in Valkenswaard, she combined her study and work in Catharina hospital in Eindhoven as an x-ray technician. After graduating she started studying Biology at Wageningen University in 1996. Her graduate subject focused on the stress reaction of fishes, particularly the interaction between the immune system and the endocrine system, at the Department of Cell biology and Immunology at Wageningen University in collaboration with the Department of Experimental zoology of the Radboud University in Nijmegen. Afterwards, during her internship at the Department of Biotechnology at Numico Research B.V. in Wageningen, she studied the permeability of intestinal cells of patients with inflammatory bowel diseases.

In 2001 she started as a data manager at CTO/Clinquest Europe in Oss, where she performed and coordinated several (inter)national clinical studies/trials.

From 2008-2018, she coordinated the trauma registry in the province of Noord-Brabant at Traumacentrum Brabant/ Netwerk Acute Zorg Brabant (NAZB). Along with hospital staff in that region, a Brabant-wide trauma registration was achieved. Besides, she became registered as an epidemiologist and conducted most work of this thesis during that period.

Since 2018 she has been working at Landelijk Netwerk Acute Zorg (LNAZ), where she supports the regional trauma centres to further optimize the Dutch trauma registry and to make the national data accessible in order to improve trauma care. Besides, she supports, in close cooperation with GGD/GHOR Nederland, the regional antibiotic resistance networks in the Netherlands.

Katinka is married to Jeroen van Delft and they have two children, Jasper and Isa.

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